The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD)

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THESIS PORTFOLIO: CANDIDATE DECLARATION

Title of degree programme	**Professional Doctorate in Clinical Psychology**
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Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed:  Date: 20/07/2020

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To my research supervisors, Helen Scott and Stephanie Hutton, thank you for being on hand with care, encouragement and expertise throughout the writing of this thesis, and often going out of your way to provide this. Thank you also to Bro for your help with proof-reading: I am very lucky to still have you helping me with theses eight years after our last one!

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Contents

Thesis abstract

Non-epileptic Attack Disorder (NEAD) is the most commonly diagnosed functional neurological disorder worldwide. It is characterised by episodes which outwardly resemble epileptic seizures but have no discernible organic origin. Psychological therapy is the recommended treatment for NEAD. Those with the diagnosis, however, can be reluctant to engage with psychological therapy, believing seizures have an organic cause. Family carers have been found to be more accepting of the role of psychological factors in NEAD but have received little research attention to date.

Paper one is a literature review. It aimed to provide an updated synthesis and critical appraisal of research evaluating the impact of psychological interventions on seizure frequency and/ or Quality of Life (QoL) in adults diagnosed with NEAD. Eleven studies were identified for inclusion; all measured seizure frequency and seven also measured QoL. All studies, except those which evaluated psychoeducational interventions, found improvements in QoL and reductions in seizure frequency post- intervention. Although results are promising in suggesting a range of psychological approaches may be of benefit to those diagnosed with NEAD, firm conclusions cannot be drawn because of the considerable variability in study quality and design.

Paper two is an empirical paper which sought to explore the experiences of people caring for an adult family member diagnosed with NEAD. Eight family carers (four mothers and four spouses) participated in semi-structured Skype interviews. Three superordinate themes and ten subordinate themes were developed from interview data using Interpretative Phenomenological Analysis. Subordinate themes related to the personal impact of caring, navigating the reactions of others, and the importance of having an explanatory framework for seizures. Collaborative relationships with professionals, and the provision of information which led to carer

understanding of seizures was described to facilitate change in caring approach and carer wellbeing.

Paper three is an executive summary of paper two, produced as an accessible document to share the rationale, aim, method, findings and implications of the empirical paper with those who participated. This document was developed in consultation with a family carer for somebody with NEAD.

Paper One: Literature review

Psychological interventions for Non-epileptic Attack Disorder (NEAD): a literature review focusing on quality of life and seizure frequency outcomes.

Word Count: 7955

Target Journal: Epilepsy and Behavior
(See Appendix A for journal submission guidelines)

Abstract

Background: Non-Epileptic Attack Disorder (NEAD) is characterised by seizures that outwardly resemble epileptic seizures but have no discernible organic origin. People diagnosed with NEAD have been found to have a lower Quality of Life (QoL) than those with epilepsy. Past reviews have, however, concluded there is insufficient reliable evidence to determine the effectiveness of psychological interventions in reducing seizure frequency and improving the QoL of life of people with NEAD.

Purpose: The present review aims to provide an updated synthesis and critical appraisal of research evaluating the impact of psychological interventions on seizure frequency and/ or QoL in adults diagnosed with NEAD.

Method: A systematic literature search of four online databases (CINAHL, EMBASE, MEDLINE and PsycInfo) was undertaken in June 2019. Eligible studies were appraised using the Modified Downs-Black tool and results synthesised narratively.

Results: Eleven studies met inclusion criteria for review; all measured seizure frequency and seven measured QoL. Studies evaluated a range of psychological interventions including Cognitive Behaviour Therapy (CBT), Dialectical Behaviour Therapy (DBT) and mindfulness. All studies except those evaluating psychoeducation interventions reported improvements in QOL and reductions in seizure frequency following intervention.

Conclusions: The capacity to draw conclusions from this review is limited by the varied designs and methodological quality of included studies. The positive results reported do however provide preliminary indications that several different psychological interventions may be effective in reducing seizure frequency and improving the QoL of individuals diagnosed with NEAD. More methodologically rigorous studies are required before firm conclusions can be drawn.

1. Introduction

1.1. Non- epileptic Attack Disorder (NEAD)

Non- epileptic Attack Disorder is characterised by episodes that outwardly resemble epileptic seizures yet are not accompanied by epileptiform activity in the brain; they have no currently discernible organic cause [1]. As many as fifteen different terms have been used to refer to the condition with Non-Epileptic Attack Disorder (NEAD), Psychogenic Non-Epileptic Seizures (PNES) and pseudoseizures being the most frequent in current use [2,3]. Several of these terms are experienced as pejorative; the term NEAD will be used in this review as endorsed by service users [2].

NEAD is estimated to have a prevalence of 2-33 per 100,000 and represents the most commonly diagnosed functional neurological condition worldwide [4,5]. Gold standard diagnosis involves the exclusion of epilepsy using video electroencephalogram (VEEG) monitoring during seizures [6]. Research highlights substantial variation in care provision with no current standardised care pathway or natural home speciality for individuals with NEAD [6,7]. Indeed, one study reported average delays of seven years from first seizure to diagnosis in 68 patients presenting at a UK based seizure clinic for the first time, with even longer delays for individuals who experience both epileptic and non-epileptic seizures [8]. Prior to correct diagnosis, individuals often present for medical attention in accident and emergency departments, and can be prescribed high doses of unnecessary anticonvulsant medication to treat what is often misdiagnosed as refractory epilepsy [9].

A systematic review of research into health professionals' perceptions of NEAD revealed high levels of uncertainty about the diagnosis and who is responsible for its treatment, as well as anticipation of poor prognosis [7]. This review also highlighted stigmatising views amongst healthcare staff, especially amongst non-

specialist staff [7]. One included study, for example, reported that 70% of a sample of American emergency care staff believed non-epileptic seizures were caused by alcohol use, compared to just 20% of neurology ward staff [10].

NEAD is reported to be almost three times more prevalent in women than men, with seizures typically beginning in young adulthood [11]. A recent systematic review concluded that factors such as a history of trauma and neglect, over-reporting of physical symptoms and avoidant coping styles are commonly associated with the diagnosis of NEAD and suggest these may represent predisposing factors [12]. The quality of research evidence contributing to this review was, however, acknowledged to be low to medium. The association between previous traumatic experiences and NEAD represents the most well studied of possible predisposing factors. A previous systematic review and meta-analysis found, for example, that 35.7% of individuals with NEAD across 15 studies reported having been sexually abused as children, compared to 16.7% of participants in study comparison groups (typically consisting of individuals with epilepsy) [13]. Included studies did, however, employ diverse definitions of sexual abuse and reported prevalence rates ranging from 5.9% to 84.6%, making it difficult for the review authors to draw reliable comparisons.

1.2 Psychological impact of NEAD

A systematic review of qualitative research conducted with people diagnosed with NEAD identified confusion and uncertainty as commonplace following diagnosis, with people being surprised to be given a psychological, rather than physical, explanation for their difficulties [14]. A sense of 'post-diagnostic limbo' can reportedly follow [15], with little in the way of perceived support immediately after diagnosis. A perceived lack of understanding from, and negative interactions with, health professionals are also frequently reported in the literature [14], as is a sense of isolation and loss following changes in personal freedom, independence,

privacy, and employment [15]. Low-mood, anxiety and self-esteem difficulties are also reported to be common following diagnosis [16].

1.3. Psychological models and interventions

There are multiple psychological models of NEAD and the diagnosis is not without controversy, some questioning whether it is best understood as a symptom of other psychological difficulties rather than a stand-alone diagnosis [17]. Traditional psychodynamic models propose NEAD results from the conversion of psychological distress into physical symptoms [18], and further contemporary developments of this approach suggest seizures represent an unconscious defensive response that serves to supress an emotion or escape interpersonal conflict [19]. Myers, Vaidya-Mathur and Lancan [17] propose NEAD may instead be understood as a type of dissociative response to internal or external triggers of trauma memories. Learning theorists propose that NEAD may in some instances represent a learned behaviour that is reinforced through the principles of operant conditioning; people with NEAD learning through observation or experience that seizures are a method of securing required care [20]. Indeed, prior knowledge and/ or experience of seizures has been found to be significantly higher amongst those diagnosed with NEAD as opposed to epilepsy, with one study reporting 66% of 27 individuals with NEAD had prior experience of seizures as compared to 11% of 35 individuals with epilepsy [21]. Yet further models of NEAD propose seizures can be understood as a hard-wired behavioural tendency similar to fight, flight or freeze defensive stress responses that serve to regulate arousal and ultimately, ensure survival [22].

It is acknowledged that none of the above-mentioned conceptualisations can explain all instances of NEAD. For example, whilst NEAD may sometimes represent a dissociative response to a trauma trigger, not everyone who experiences NEAD reports a history of trauma. In 2016, Brown and Reuber [23] proposed the Integrative Cognitive Model (ICM) as an attempted overarching

account of existing theories. The ICM views NEAD as a heterogeneous condition that can result from a range of different, interacting factors. These factors are all accounted for within the model yet will not all be relevant in every instance of NEAD. The model is based in cognitive psychology and proposes that individuals with NEAD have a seizure representation in memory, termed the *seizure scaffold*. This seizure scaffold is developed through knowledge and experience of seizures (e.g. witnessing seizures in others or in the media/ experiencing illness, trauma, loss of consciousness or injury). It interacts with the individual's automatic behavioural response tendencies (e.g. hard-wired fear-escape response) triggered by internal or external cues interpreted as threatening (e.g. traumatic memories, certain levels of arousal or certain stimuli). When arousal levels are altered, such as at times of chronic stress or during illness, the inhibitory processing which normally prevents non-epileptic seizures is compromised and the seizure scaffold is more easily activated, triggering a seizure.

The ICM is a relatively recent model of NEAD and represents an extension of the Integrated Cognitive Model (ICM) for medically unexplained symptoms [24]. Brown and Reuber [23] acknowledge that concepts such as the seizure scaffold may be empirically challenging to investigate due to their hypothesised location outside of conscious awareness. The model has been well received, however, due to its proposal that no single factor is necessary nor sufficient in explaining all instances of NEAD, and its inclusion of factors such as altered inhibition and arousal in addition to purely psychological factors [25]. It has also been described as clinically useful in encouraging clinicians to consider a wide range of factors when formulating a particular individual's seizures and selecting a suitable psychological approach [26]. An audit published by Duncan et al. in which therapeutic approaches were selected on the basis of client presentation provides initial evidence for such a formulation driven approach [27]: 43 of 81 participants reported being seizure-free for two-months, six-months after intervention. Factors such as a lack of comparison conditions must be held in mind, however, when considering this finding.

As yet, there are no standardised treatment guidelines for NEAD [6]. National Institute for Clinical Excellence (NICE) guidelines for the treatment of epilepsy briefly state: “Where Non-Epileptic Attack Disorder is suspected, suitable referral should be made to psychological or psychiatric services for further investigation and treatment (1.5.7)” [28]. This advice was last updated in 2004 and provides no specific guidance on psychological approach. For example, there is no guidance on recommended interventions when non-epileptic seizures are concurrent with other mental health conditions, as is frequently the case. A systematic review by Bodde et al. reported, for example, that across 65 research papers, participants diagnosed with NEAD also commonly had psychiatric diagnoses of mood disorder (64%), personality disorder (62%), PTSD (49%) or other anxiety disorders (47%) [29].

1.4. Quality of Life (QoL) and seizure frequency

In spite of similar outwards symptom profiles, research has consistently found that people with a diagnosis of NEAD report significantly lower health related QoL than those diagnosed with epilepsy [30,31].

Health Related Quality of Life (HRQoL) represents an individual’s subjective perception of the impact of their health condition and its treatment on their everyday life, psychological wellbeing, social functioning and independence [32]. In contrast to the broader, overarching concept of Quality of Life (QoL), HRQoL focuses solely on the impact of an individual’s health [33], although both terms can be found used interchangeably in current literature [34].

Research with individuals with epilepsy has found that QoL improves with seizure reduction [35]. This relationship is less clear in those diagnosed with NEAD. In a 2016 systematic review, Jones et al. reported that seizure frequency is not a predictor of QoL in people diagnosed with NEAD and concluded that psychological

and interpersonal factors are more influential [36]. Depressive symptoms were identified as the strongest predictor of QoL followed by dissociation, increased reporting of somatic symptoms (e.g. headaches), avoidance of emotional difficulties and family relational difficulties. The review authors did however highlight research conducted by Quigg et al. [37] which found that seizure cessation, rather than reduction, was associated with improved QoL. Research published since the review of Jones et al. has also reported findings contrary to their conclusions. Robson et al., for example, reported that reductions in the frequency of non-epileptic seizures were associated with improved QoL in their sample of 115 individuals with NEAD [38]. Until it is established whether reduction in seizure frequency necessarily leads to improved QoL for those with NEAD, both seizure reduction and QoL are considered valuable outcomes for current study.

1.5. Previous reviews of the literature

Two previous systematic reviews have examined the research evidence for psychological interventions for NEAD. A Cochrane review published in 2014 [39] reviewed the effects of psychological and behavioural interventions on QoL and seizure frequency in twelve studies conducted between 1982 and 2010. The authors identified a randomised control trial of Cognitive Behaviour Therapy (CBT) conducted by Goldstein et al. [40] as the strongest evidence of an effective intervention but concluded that, overall, there was insufficient reliable evidence to support psychological intervention for NEAD; nine of the twelve included studies rated as having high risk of bias and only four including a measure of QoL.

A more recent 2017 meta-analytic systematic review [41] focused on the effects of psychological interventions on seizure frequency and cessation in 13 studies published between 2001 and 2014. Meta-analysis revealed that 82.5% of those who completed psychological therapy reported a greater than 50% reduction in seizure frequency, with 47% becoming seizure free. Both analyses were however conducted on a per protocol basis, meaning that reported effects relate only to

those individuals who completed the offered interventions. Analyses were also based on the first available time point where studies had multiple follow-up points. In combination, these factors likely result in meta-analytic conclusions representing best case, rather than typical, outcome data.

1.6. Review aims and rationale

Seizure frequency represents the dominant outcome measure used in the extant NEAD literature [36-38]. However, whilst seizure reduction has been found to correlate with improved QoL in epilepsy [30,31], the relationship between improvements in seizure frequency and the QoL of individuals with NEAD remains unclear [36]. Reductions in the frequency of non-epileptic seizures may not necessarily result in simultaneous improvements in QoL for those diagnosed with NEAD. QoL has also been identified as an important outcome measure by individuals who experience seizures themselves [42]. Both seizure frequency and QoL outcomes are therefore considered in this review, which will provide an up-to-date synthesis of research in the area. The review will be a narrative synthesis; meaningful meta-analysis considered to be precluded by the diversity of designs, interventions and outcome measures employed in identified research. An updated review is considered timely given the current absence of a standardised care pathway or psychological intervention guidelines for NEAD. It is also hoped that the results of the review will aid clinical decision making about appropriate support for individuals diagnosed with NEAD.

This review will update and extend previous reviews in order to answer the research question: “Do psychological interventions with adults diagnosed with NEAD lead to improvements in seizure frequency and/or quality of life?”

2. Method

2.1. Search strategy

CINAHL, EMBASE, MEDLINE and PsycInfo were individually searched through the NICE Healthcare Database Advanced Search (HDAS) on 08/06/2019. Searches for the previous review which considered QoL outcomes were conducted in February 2013. The present review therefore employed a date limiter (2011-2019) to ensure any research not previously considered was identified. Following the removal of duplicates, titles and abstracts were screened against inclusion criteria and full text articles sought if relevance was indicated. Backwards and forwards citation tracking was then employed; reference lists of identified articles were hand searched and Google Scholar used to identify any subsequent articles citing papers included in the review. The flow diagram in Figure 1 shows the process of identifying papers.

2.2. Publication bias

Unpublished literature was searched via Open Grey, Ethos and email communication with authors to enable a qualitative analysis of possible publication bias; the increased likelihood of publication for studies reporting positive results [43]. No additional studies were identified for inclusion in this way.

2.3. Search terms

Search terms were developed using the PICO (Participants, Intervention, Comparator and Outcome) framework [44] and related to 1.) NEAD 2.) psychological interventions and 3.) seizure frequency and QoL outcomes. A wide variety of terms are used to refer to non-epileptic seizures in the extant literature and extensive search terms were thus used to capture all relevant literature (see Table 1 for search terms). Previous literature reviews [39,41,45] were consulted to identify relevant terms and an NHS reference librarian consulted about both search terms and effective use of the HDAS database.

Table 1: *Search Terms employed in HDAS database searches*

PICO Category	Search Terms
Population	Non epileptic seizure* OR nonepileptic seizure* OR non epileptic attack* OR nonepileptic attack* OR "NEAD" OR psychogenic non epileptic seizure* OR psychogenic nonepileptic seizure* OR "PNES" OR dissociative seizure* OR dissociative attack* OR functional seizure* OR pseudo seizure* OR pseudoseizure* OR pseudo epilep* OR pseudoepilep* OR conversion seizure* OR conversion disorder* OR hysterical seizure* AND
Intervention	Therap* OR psycholog* OR psychotherap* OR intervention OR treatment OR psychoanaly* OR psychodynamic OR group therap* OR counsel* OR psychoed* OR education OR cognitive behavio* OR behavio* OR CBT OR "acceptance and commitment therapy" OR ACT OR "compassion focused therapy" OR CFT OR "dialectical behavio* therapy" OR DBT OR "cognitive analytic therapy" OR CAT OR mindfulness OR MBSR OR MBCT OR "eye movement desensitization and reprocessing" OR EMDR OR "Interpersonal therapy" OR IPT OR relaxation OR imagery OR hypno* OR paradoxical AND
Outcome	"Quality of life" OR QoL OR "health related quality of life" OR HRQoL OR QoLiE OR "seizure frequency" OR "seizure reduc*" OR "seizure free*"

2.4. Inclusion and exclusion criteria

Eligibility criteria for inclusion are outlined below alongside their rationale and working definitions of terms used.

Inclusion criteria:

- Primary research study published in a peer reviewed journal.
  - Peer review adds an additional level of quality appraisal.
- Sample consists of adults aged 18+ years with a diagnosis of NEAD.
  - The aetiology, course and prognosis of NEAD in children is different to that in adult populations [46] and therefore merits separate consideration.
- Psychological therapy intervention study.
  - Psychological therapy is defined as any intervention involving a verbal dialogue between a trained facilitator and a person with NEAD based on psychological theory. The intervention may be in any format (e.g. group, individual, telephone).

- Seizure frequency, Quality of Life (QoL) or both are included as outcome measures.
  - QoL and HRQoL are used interchangeably within the extant literature [47] and studies measuring either will thus be included.
  - Measures of either seizure frequency or cessation will be included.
- Published in the English language.
  - Resources for translation were unfortunately not available.

Exclusion criteria:

- Information/ education only interventions.
  - Such interventions do not meet the review's definition of psychological therapy.
- Audits, service evaluations and descriptive case studies/ series not suitable for analysis at group level.
  - The review seeks to synthesise best available evidence.

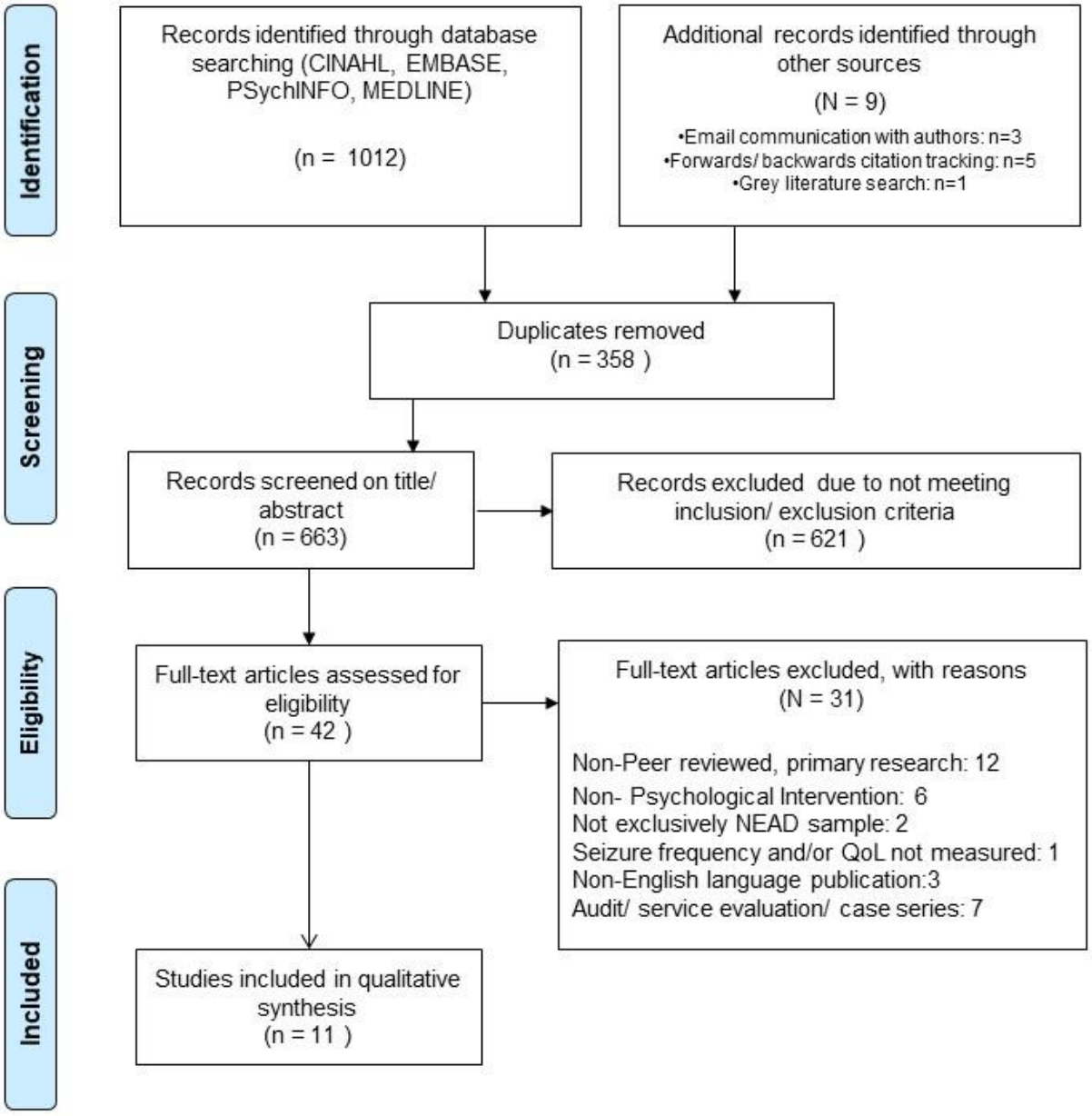

Figure 1: PRISMA flow diagram demonstrating search strategy

2.5. Data extraction

A standardised data extraction form was developed and used to extract relevant data from all included studies. An example data extraction form is provided in Appendix B for reference.

2.6. Quality assessment

Study quality was assessed using the Modified Downs-Black Checklist [48] (Appendix C). A previous systematic review of appraisal tools identified this checklist as appropriate for use in reviews appraising both randomised and observational study designs [49]. The checklist generates both an overall quality score and composite scores for the domains of reporting, internal validity, external validity and power. It has been found to have good internal consistency (KR-20= 0.89), test-retest reliability (r=0.88), inter-rater reliability (r=0.75), and concurrent validity with existing established quality assessment instruments (r=0.9) [48].

Alterations were made to maximise the utility of the Modified Downs-Black tool for the purposes of the present review. Item 18 relating to the use of appropriate outcome measures, and item 20 relating to appropriate statistical analyses were adjusted to include a third response option for partial satisfaction of the criteria. Studies were rated as having partially satisfied the criteria for these items if outcome measure selection or statistical analysis was appropriate for one of the two focal outcome measures (seizure frequency and HRQoL). Item 27, relating to statistical power was simplified from a five-point response to a binary response: a score of one indicating that a study was adequately powered and a score of zero indicating that a study was either underpowered or that a power calculation had not been reported. This particular adjustment is commonplace with the use of the Modified Downs-Black tool in systematic reviews when insufficient information is available to permit scoring with the original five-point scale [50-52]. The impact of such amendments on the psychometric properties of the Downs-Black tool are not known. Amendments did, however, confer the possibility of a finer level of quality

analysis in relation to the aims of this review, and were considered appropriate given the narrative nature of the review. The resultant tool had a total possible score of 30 for controlled studies and 26 for non-controlled pre-post studies. The domain and total quality scores awarded to included studies can be seen in Appendix D.

3. Results

3.1. Study characteristics

The search yielded 11 studies that met inclusion criteria for review (Table 2). Included studies consisted of two Randomised Controlled Trials (RCTs) [53,54], two pilot RCTs [55,56], two quasi experimental pre-post controlled studies [57,58], and five non-controlled pre-post studies [17,59-62], two of which were pilot/ feasibility studies [61,62]. Three of the included studies included a follow-up time point [17,55,60] with follow-up periods varying from one to 34 months [17]. Sample sizes ranged from nine [60] to 105 [54].

3.2. Outcome measures

All reviewed studies included a self-report measure of seizure frequency with eight of the eleven studies also reporting on seizure cessation [17,53,54,58-62]. Seven studies also included measures of HRQoL [53,54,56-58,60,62]. HRQoL was measured using both epilepsy specific measures (Quality of Life in Epilepsy, 10 item version (QOLIE10) [54,58] and Quality of Life in Epilepsy, 31 item version (QOLIE 31) [53,54,58]), and broader HRQoL measures (36-Item Short Form Health Survey Questionnaire (SF36): [57,60,62]). The SF36 [63] is a multi-item scale that measures eight health concepts such as limitations in physical activities because of health problems, and vitality (energy and fatigue). Scores on these eight subscales can be combined to form the physical component summary score and the mental component summary score.

A summary of included studies can be found below and in Table 2. As the present review is focused on QoL and seizure frequency, only findings related to these two factors are reported and appraised.

3.3. Overview of included studies

Bullock et al. [61] recruited 21 outpatients diagnosed with NEAD and offered a 30-week Dialectical Behaviour Therapy (DBT) skills training group. The group taught stress tolerance, emotional regulation, interpersonal effectiveness and mindfulness skills. Participants also attended individual therapy. Pre-post intervention changes in self-reported weekly seizure frequency were analysed.

Chen et al. [55] recruited 64 veterans diagnosed with NEAD in the past four weeks from a veterans medical centre. Participants were randomised to receive either standard medical care or a three-session group psychoeducation intervention that introduced psychological explanations of NEAD and strategies such as relaxation, stress management and trigger identification. Change in seizure frequency was measured pre- and post- intervention using participant Likert scale ratings of improvement (e.g. “about twice as bad as before”; “more than twice as bad as before”).

De Barros et al. [57] recruited 47 participants by screening all patients diagnosed with NEAD and refractory mesial temporal lobe epilepsy treated at a tertiary epilepsy centre. An eight-session group CBT program targeting symptoms of anxiety and depression was offered. Seizure frequency and HRQoL were measured pre- and post-intervention using self-report and the SF36, respectively. Participants who could not commit to attending all eight sessions were used as a comparison group for analysis.

De Oliveira Santos et al. [59] offered 48 sessions of individual psychoanalysis to their sample of 37 outpatients with NEAD who had been consecutively referred for outpatient psychoanalytic treatment. Clinicians rated whether seizures had reduced, stopped or not-stopped following intervention.

La France et al. [53] conducted a multi-site RCT across three academic medical centres. Thirty-eight participants with NEAD were randomised to receive either 12 sessions of CBT, CBT plus medication, medication only or standard medical care. Seizure frequency and HRQoL were measured at baseline, midpoint and post-intervention, using self-report and the QOLIE-31.

Mayor et al. [62] recruited 29 outpatients diagnosed with NEAD in the past four weeks and evaluated a four-session individual psychoeducation intervention. Monthly seizure frequency and HRQOL were measured at baseline and at 7-month follow-up using self-report and the 36 Item Short Form Survey (SF36), respectively.

Metin et al. [60] delivered a 12 session “mixed psychotherapy” group to a sample of 13 individuals described as non-responsive to previous psychiatric care for NEAD. The intervention involved psychoeducation and psychodynamic informed exploration of unconscious motivations for seizures. Self-reported monthly seizure frequency was measured at baseline and at several follow-up points up to 12 months. QoL, as measured by the SF36, was measured pre- and post-intervention.

Myers et al. [17] recruited 18 adults diagnosed with both NEAD and Post Traumatic Stress Disorder (PTSD). Participants were offered twelve sessions of Prolonged Exposure Therapy (PET); a specific form of CBT developed for post-traumatic stress. Self-reported seizure frequency was measured at baseline, post-intervention and 1- to 34-month follow-up.

Thompson et al. [56] delivered a single session, conversational intervention aimed at reframing unhelpful beliefs about NEAD with 19 participants who had been diagnosed immediately prior. Seizure frequency and HRQoL were measured at baseline and six to eight-week follow-up using self-report and the QOLIE-31.

Tolchin et al. [58] consecutively recruited 105 adults with NEAD from a specialist quaternary care centre and evaluated a 12 session individual mindfulness intervention. Seizure frequency and QoL were measured pre-intervention and at 12-24-month follow-up, using self-report and the QOLIE-10, respectively. For analysis, participants were grouped by those who had attended at least eight of the twelve sessions offered and those who had not.

Tolchin et al. [54] consecutively recruited 60 adults with NEAD from both inpatient and outpatient settings and randomised them to a twelve session mindfulness intervention with or without an initial thirty minute motivational interviewing (MI) session. HRQoL and seizure frequency/ cessation were measured pre-intervention and at 16- week follow-up using self-report and the QOLIE- 10.

Table 2: *Overview of included studies and quality score awarded using Modified Downs-Black Checklist*

						Outcome Measures & Outcome		
Author (Year) & Country	**Study Design**	**Sample at enrolment**	**Intervention & Duration**	**Comparison group**	**Measurement points**	**Seizure Frequency**	**QoL**	**Total quality score**
Bullock et al. (2015) USA [61]	Non-controlled, pre-post, pilot study	N=21 outpatients with NEAD n=2 had concurrent epilepsy.	DBT-skills training group (n=7 per group) 90m weekly sessions Average length 20.5 weeks	N/A	Pre- and post-intervention	Self- report weekly seizure frequency Pre-post reduction in average seizure rate from 14 to 5 per week (t=-3.76, df=17, p=0.002). n=9/17 >50% reduction in seizure frequency. n=6/17 (35.3%) seizure cessation	N/A	16/26 61.5%
Chen et al. (2014) USA [55]	Pilot RCT	N=64 veterans diagnosed with NEAD in past 4 weeks. Concurrent epilepsy = exclusion criteria.	Group Psychoeducation (n=3-10 per group) 3 x monthly 1.5h group sessions	Standard medical care (n=30)	Pre-intervention, post-intervention and 3-month follow-up	Likert rating of change in seizure frequency No significant difference in seizure frequency between groups at post-intervention or follow-up.	N/A	20/30 66.7%

De Barros et al. (2018) Brazil [57]	Quasi-experimental pre-post controlled study	N=47 adult outpatients with NEAD and refractory mesial temporal lobe epilepsy	Group CBT (n=8 per group) for anxiety & depression 8x weekly sessions (duration not stated)	Standard medical care (n=23 individuals who indicated they could not attend all 8 sessions of intervention condition)	Pre- and post-intervention	Self-reported weekly seizure frequency Significantly greater reduction in weekly seizure frequency in intervention group relative to control group (p<0.02).	SF36 Significant pre-post improvement on functional capacity (p<0.03, d= 0.41), physical (p<0.03, d=0.42) and emotional (p<0.02, d=0.41) subscale scores of SF36 in intervention group.	17/30 56.7%
De Oliveira Santos (2014) Brazil [59]	Non-controlled, pre-post study	N=37 adult outpatients with NEAD n=10 had concurrent epilepsy	Individual Psychoanalysis 48 x 50-minute weekly sessions	N/A	Pre- and post-intervention	Clinician rated change in seizure frequency (reduced/stopped/not reduced) n=19/37 (54.1%) experienced pre-post seizure reduction (magnitude not stated) n=11/37 (29.8%) seizure cessation. Significantly higher rates of seizure cessation/ reduction in intervention completers (N=18/18), p<0.01.	N/A	12/26 46.2%

La France et al. (2014) USA [53]	Multi-site RCT	N=38 adult outpatients with NEAD recruited from three academic medical centres. Concurrent epilepsy=exclusion criteria	Individual CBT (n=9) 12 x 60-minute weekly sessions	1. CBT + sertraline (n=10) 2. Sertraline only (n=9) 3. TAU (n=10)	Pre- and post-intervention	Self-report monthly seizure frequency CBT: average pre-post reduction of 51.4% ($p<0.02$), 55.6% >50% seizure reduction; n=3/9 (33.3%) seizure cessation. CBT+ sertraline: average pre-post reduction of 59.3% ($p<0.008$); 66.7% >50% seizure reduction; n=5/9 (55.6%) seizure cessation. TAU/ Sertraline only: no significant change.	QOLIE-31 & QOL-FB CBT: significant improvement on QOLIE 31 ($p<0.001$; d=1.8) & QOL-FB ($p<0.05$; d= -1.1) CBT+ sertraline: significant improvement on QOL- FB ($p<0.01$, d=-0.9) TAU/ Sertraline only: no significant change	13/30 43.3%
Mayor et al. (2013) UK [62]	Non-controlled pre-post feasibility study	N=29 adults with NEAD diagnosed approximately 4 weeks ago Individuals with epilepsy included if no epileptic seizure in past 12 months.	Individual psychoeducation 4x 60 min weekly sessions	N/A	Pre-intervention and 7-month follow-up (IQR: 5.5-9 months)	Self-report monthly seizure frequency No change in average monthly seizure frequency from baseline to follow-up n=4/13 (30.7%) seizure free at FU.	SF36 Descriptive improvement on SF36 physical and mental health component summary scores pre-post intervention.	12/30 40%

Metin et al. (2013) Turkey [60]	Non-controlled pre-post study	N=13 adults with NEAD considered not responsive to previous psychiatric care.	Eclectic group psychotherapy 12x 90m weekly sessions	N/A	Pre-intervention, post intervention, 4, 6, 9- and 12-month follow-up (follow-up for seizure data only)	Self-report monthly seizure frequency Significant decrease in seizure frequency from baseline to 12-month FU ($p<0.0001$). All participants: >50% reduction in seizure frequency at 12m FU. N=6/9 (66.6%) seizure free at 12m FU.	SF36 Significant improvement on mental health subscale from pre-post intervention ($p<0.03$)	12/30 40%
Myers et al. (2017) USA [17]	Non-controlled pre-post study	N=18 adults with NEAD and diagnosis of PTSD.	Individual Prolonged exposure therapy 12-15 x 90m sessions	N/A	Baseline, post intervention and naturalistic follow-up (Range 1-34 months)	Self-report daily seizure frequency Significant decrease in seizure frequency pre-post intervention ($p<0.001$) and at follow-up ($p<0.028$). n=13/16 (81.3%) completers seizure free at post-intervention. n=3/16 completers: seizure reduction post intervention ($p<0.001$)	N/A	9/26 34.6%

Thompson et al. (2012) USA [56]	Pilot RCT	N=19 adult inpatients diagnosed with NEAD immediately prior. Epilepsy= exclusion criteria	Individual Psychoeducation/ reframing (n=9) 1x 40-90-minute session	Standard medical care (n=10)	Baseline and 6-8-week follow-up.	Self-report seizure frequency No significant reduction in seizure frequency from baseline to follow-up	QOLIE-31 No significant change from baseline to follow-up	15/30 50%
Tolchin et al. (2019) USA [58]	Quasi-experimental pre-post controlled study	N=105 outpatients with NEAD from specialist quaternary care centre. n=14 had concurrent epilepsy but could distinguish between their epileptic and non-epileptic seizures.	Individual Mindfulness 12 x 60-minute weekly sessions	'Non-adherent to intervention' group (attended <8 sessions over 16 weeks) (n=56)	Baseline and 12-24-month follow-up	>50% seizure reduction and seizure freedom for >3 months at follow-up. Significantly greater proportion of participants attaining >50% reduction in seizure frequency at follow-up in 'adherent' than 'non-adherent' group (84% vs 61%, p<0.021) No difference in proportion of 'adherent' and 'non-adherent' participants reporting being seizure free for 3 months at follow-up (70% vs. 57%, respectively; p<0.269).	QOLIE-10 Significantly larger improvement in 'adherent' than 'non-adherent' group (p<0.044, d=0.5)	15/26 57.7%

Tolchin et al. (2019) USA [54]	RCT	N=60 inpatients/ outpatients with NEAD.	Individual Mindfulness plus 30m motivational interviewing session before intervention began (n=29) 12 x 60-minute weekly sessions	Individual mindfulness (n=31) 12 x 60-minute weekly sessions	Baseline and 16-week blinded telephone follow-up interview	Percentage change in NEAD frequency & seizure free for at least 1 month at follow -up Significantly greater percentage reduction in Mindfulness+ MI group (76.2% vs 34.8%, p<0.034, d=0.59). No significant difference in seizure freedom between Mindfulness + MI (n=8/26; 30.8%) and Mindfulness condition (n=3/29; 10.3%)	QOLIE-10 Significantly greater improvement in mindfulness + MI condition relative to mindfulness only condition (p<0.047; d=0.6)	21/30 70%

Table Key:
Interventions: ACT= Acceptance and Commitment Therapy; CBT= Cognitive Behavioural Therapy; DBT= Dialectical Behaviour Therapy.
Measures: QOLIE-10= Quality of life in Epilepsy questionnaire, 10 item version; QOLIE-31= Quality of Life in Epilepsy, 31 item version; SF36= Short Form health survey; QOL-FB- Quality of Life Burden to Family Subscale.

3.4. Summary of results

Study quality, as rated by the Modified Downs-Black appraisal tool [48], varied from 34.6% to 70%. Ratings for individual studies can be seen in Appendix D. Lower quality studies were not excluded from the review so discussion of their design and methodological quality could inform future research.

Statistically significant reductions in seizure frequency were observed following psychological intervention in eight of the eleven studies and were reported both immediately post-intervention [17,53,57,59,61] and at follow-up points ranging from one to 34 months [17,54,58,60]. Only one study [54] reported on effect size, however, meaning that it is not known whether observed changes in seizure frequency were clinically, as well as statistically, significant overall. The three studies that did not find any significant change in seizure frequency were those which employed short-term psychoeducational interventions [55,56,62].

Eight studies reported that seizure frequency reduced to the point of cessation in a percentage of participants [17,53,54,58-62]. The proportion of participants obtaining seizure freedom varied significantly, ranging from 33.3% [53] to 81.3% [17] immediately post-intervention and between 10.7% [54] to 66.7% [60] at follow-up. La France reported that the odds of achieving seizure freedom was 6.2 times greater for those who received CBT across any of the arms of their trial relative to those who did not [53].

Five of the seven studies which measured HRQoL reported statistically significant improvements on this dimension following intervention, with studies reporting improvements in QoL both immediately post-intervention [53,57,60] and at follow-up [54,58]. Where reported, effect sizes varied; De Barros et al. reported a small effect [57], Tolchin et al. reported moderate effects [54,58] and La France et al. reported a large effect [53]. The reframing intervention study of Thompson et al. [56] reported a descriptive improvement to QoL as measured by the QOLIE-31, although this effect was not statistically significant. Mayor et al. [62] also reported a descriptive improvement in this direction but did not

examine the statistical significance of this change due to the study's nature as a feasibility study.

Studies which used the SF36 varied in terms of whether they reported on changes to individual subscales or the overall mental and physical health component summary scores to which these subscales contribute. Metin et al. [60] and De Barros et al. [57] reported on individual subscales; the former finding statistically significant improvements to the mental health subscale and the later small, statistically significant effects on the functional capacity (d=0.41), physical aspects (d=0.42) and emotional aspects subscales (d=0.41). These results indicated that participants felt everyday activities and physical activities were less affected by health and emotional problems following intervention. Mayor et al. [62] instead reported on the overall component summary scores, finding descriptive improvements across both the mental and physical health summary scores. As previously noted, however, Mayor et al. did not employ inferential statistical testing due to their study's nature as a feasibility study and it is therefore not known whether this change was statistically significant.

In terms of potential moderating factors, completion of the intervention [57,58] and the addition of a preliminary session of motivational interviewing [54] lead to statistically greater post-intervention improvements in QoL and seizure frequency, but not higher rates of seizure cessation [54,58]. La France et al. [53] also reported that CBT in combination with medication resulted in descriptively larger effects on seizure frequency and rates of seizure cessation than CBT alone. This pattern of results was not replicated on QoL outcomes: large improvements in QoL were reported in the CBT arm and only moderate improvements in the CBT plus medication arm. The study was, nevertheless, not intended to be powered for between group comparisons and the statistical and/ or clinical significance of these differences is therefore not known.

4. Quality Assessment

4.1. Design and Methodology

Four studies did not include a control group [17,60-62]. The absence of control groups in these studies means it is not possible to conclude whether reported results were due to the intervention alone. For instance, all participants in the Bullock et al. [61] study had concurrent individual therapy from a variety of therapeutic approaches and it is possible this, in addition to the group DBT intervention under study, contributed to reported seizure reduction. Three further studies formed comparison groups by grouping participants who did not complete the intervention offered [57-59]. These quasi-control groups also introduce significant risk of bias. Potential differences between groups, such as attitude towards psychological understandings of NEAD, may have resulted in treatment effects appearing larger than they would have relative to true control conditions.

Seizure frequency was measured by self-report in all included studies, with self-report being transformed into a clinician categorisation in one study [59]. Although objective measurement of seizure frequency would be practically challenging, the use of self-report poses a significant threat to internal validity due to the potential for recall error and bias in reporting. This risk is amplified in the two studies which analysed seizure frequency as a categorical rather than continuous variable [55,59]. For example, Chen et al. [55] assessed changes in seizure frequency using a five-point Likert-scale rating of perceived change (e.g. “about twice as bad as before”; “more than twice as bad as before”). Such operationalisation of seizure frequency introduces further risk of bias due to the opportunity for subjective interpretation of each categorisation. Four included studies did make reference to proactive efforts to address the risks of self-report through encouraging the use of seizure logs to make estimations more objective [53,55,60,64] and enlisting family members to support the process of logging seizures [53,60].

4.2. Sample & Setting

Three of the six studies with comparison conditions reported that groups were equivalent on demographic and clinical factors taken at baseline [54,55,57] with Tolchin et al. [58] and Thompson et al. [56] not reporting on group equivalence. La France et al. [53] found that participants in the CBT plus medication condition of their trial had lower clinical scores for anxiety and depression (as measured by the Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI), respectively) than participants in the treatment as usual (TAU) condition, and lower BDI scores than participants in the medication only condition. It is therefore possible that higher clinical severity in the TAU and medication only conditions contributed to the lack of significant change to either seizure frequency or QoL in these conditions. Basic demographic information about participants (e.g. age, sex) was reported in all studies. Information relating to NEAD (e.g. time since diagnosis, time since first seizure, presence of concurrent epilepsy diagnosis or other mental health difficulties) was however absent in some studies [17,56,59-61,64], limiting understanding of study samples, group characteristics and to whom results can be generalised.

Studies differed in terms of whether individuals with epilepsy were included [57-59,61,62] or excluded [53,55,56] from participation. Of the studies that did not exclude people with concurrent epilepsy, only two described measures taken to control for this: including individuals with epilepsy only when their epilepsy was not active [62] or when they could distinguish between epileptic and non-epileptic seizures [58]. Three included studies did not provide information about whether individuals with epilepsy met criteria for inclusion [17,54,60] and thus carry significant risk of bias; reported reductions in non-epileptic seizures having the potential to have been spuriously affected by reductions in epileptic seizure frequency.

Good practice sampling methods such as consecutive sampling [54,55,58,59] or entire source population sampling [57] were employed in five studies. Remaining studies did not state how participants were identified for inclusion and there is therefore a risk that there may have been bias in participant

selection. For example, if only participants who accepted a psychological explanation for their seizures were invited to participate, samples would likely not be representative of the wider NEAD population.

4.3. Statistical Analysis:

Statistical analyses were rated as appropriate in six studies [54,57,58,60,61] and partially appropriate in the remainder. Statistical analyses rated as partially appropriate could be improved with changes such as the application of the Bonferroni adjustment to alpha levels following the use of multiple non-parametric T-Tests [55], and establishing whether seizure frequency data was normally distributed prior to conducting either parametric or non-parametric tests, rather than both [56]. Such changes would reduce the likelihood of false positive results.

Results were rated as having been clearly reported in only four of the eleven included studies [57-59,61]. A common limitation was an absence of summary data to support statistical analyses. For example, statistically significant reductions in seizure frequency were often reported without accompanying summary statistics showing the number of seizures experienced before and after intervention [17,53-56,59,60]. This precluded consideration of clinical significance. Reporting of seizure cessation data was also unclear in six included studies [17,54,58,59,61,62]. Several study samples, for example, included a small number of participants who became seizure free between recruitment and beginning the intervention [17,53,58,61,62] but only LaFrance et al. [53] excluded such participants from summary statistics about the number of participants attaining seizure freedom following intervention. This, coupled with a lack of reporting of seizure freedom at baseline in other studies [54,59] may have resulted in misrepresentative, inflated seizure cessation rates following intervention. Another limitation with reporting was that three papers did not fully detail whether statistical analyses were planned [17,53,62], introducing the risk of biased reporting to emphasise positive outcome.

Power analyses were conducted by two studies [53,54] but attrition meant that ultimately, only the RCT conducted by La France et al. [53] was powered to detect statistically significant change in seizure frequency. This was on a within subject basis only, meaning that the effectiveness of the different intervention arms of this trial could not be statistically compared. Participant attrition reported at enrolment, intervention and follow-up in all included studies is displayed in Appendix E. All but three studies [54,57,60] clearly reported this attrition data although only a minority compared the characteristics of participants who completed the intervention and those who did not [54,55,58,61]. Likewise, only Myers et al. [17] and de Santos et al. [17,59] explored reasons for attrition, providing qualitative information that participants declined involvement either because they did not want to revisit past trauma or did not agree with the NEAD diagnosis. These factors mean that overall, it is unknown whether selective attrition resulted in non-representative samples at study completion. Additionally, only three studies used intent to treat analysis to mediate the influence of attrition and ensure results were representative of the whole sample and not just those who completed the intervention [53,60,61]. Significant effects found in those studies which instead used per protocol analysis [17,54-56,58,62] may be inflated relative to the effects that would be found if intention to treat analysis had been used.

5. Discussion

This review sought to evaluate whether psychological interventions for adults diagnosed with NEAD lead to improvements in seizure frequency and/or Quality of Life (QoL). Statistically significant reductions in seizure frequency were reported in eight of the eleven included studies and significant improvements in HRQoL were reported in five of the seven studies in which this was measured. Notably, all three studies which did not report improvements to either outcome were those which delivered psychoeducation-based interventions. Critical appraisal of study quality using the modified Downs-Black assessment tool suggested variable quality, with studies being given quality ratings ranging from 35-70%. The design and quality of some included studies limits the extent to which conclusions can be confidently drawn and, ultimately, there is

insufficient evidence to conclude whether psychological intervention leads to improvements in seizure frequency and/ or QoL on the basis of extant research. Overall, however, results are promising in suggesting that further, methodologically rigorous research may find psychological intervention can effectively reduce seizure frequency and improve the QoL of adults diagnosed with NEAD.

Included studies were heterogeneous in many ways. Interventions themselves differed in terms of therapeutic approach, duration and intensity, mode of delivery (e.g. group/ individual/ systemic) and the facilitator/therapist's level of expertise. Participants in each study differed considerably on dimensions such as NEAD duration, presence or absence of concurrent epilepsy, concurrent mental health difficulties, response to previous interventions and membership of specific communities (e.g. the veteran community). Additionally, studies differed significantly in terms of design factors such as the presence and length of follow-up periods, the presence of comparison groups and outcome measures used. Meta-analysis was precluded by the significant diversity of included studies.

The finding that psychoeducational interventions did not lead to significant reductions in seizure frequency or improvements in QoL is consistent with the results of previous literature that did not meet inclusion criteria for the current review. Both Zaroff et al. [65] and Wiseman et al. [66] found no significant effect of psychoeducational interventions on seizure frequency or QoL. One hypothesis to explain these findings is that psychoeducational interventions have a different target to longer term-psychological interventions. Indeed, included psychoeducational studies reported positive results on other outcomes such as significantly higher rates of subsequent contact with mental health services [56] and better understanding of NEAD [55]. Such findings should, however, be interpreted with caution given that all psychoeducational studies contributing to this review were pilot/feasibility studies and therefore not designed to provide evidence of outcome. Several design features distinguished psychoeducational studies from others included in the review and these factors

must also be considered when interpreting review results. First, participants were recruited within four weeks of having been diagnosed with NEAD, meaning that they were at an earlier stage of their NEAD journey than those included in other studies and may have had a different level of acceptance/ understanding of the NEAD diagnosis. Psychoeducational interventions were also shorter and delivered predominantly by staff with medical backgrounds in comparison to the psychologists and therapists delivering the other included interventions. Given previous research associating greater therapist experience with better outcome [67], facilitator training and experience may have been a confounding factor. If replicated however, review results suggest that psychoeducation and longer-term psychotherapy may be best treated as two distinct approaches in future research. This is in keeping with stepped care approaches to managing NEAD adopted in Scotland [68] where the purpose of psychoeducation is seen as building engagement and communicating hope that that seizures can and do stop with psychological management, rather than directly targeting symptoms.

Other psychological interventions included in the review employed a range of therapeutic modalities including CBT, DBT, psychoanalysis, mindfulness, motivational interviewing and eclectic group approaches. All included studies reported positive outcomes for seizure frequency and HRQoL, where measured. However, only the studies of La France et al. [53] and Tolchin et al. [54] featured randomised control groups and neither were powered to detect between group differences, through design and high attrition, respectively. The large proportion of observational studies necessitates caution in generalising study results. Researchers cannot reasonably conclude that observed effects are due to the intervention rather than other uncontrolled factors in designs lacking comparison groups. For example, it has been found that some individuals diagnosed with NEAD can experience seizure cessation following communication of the diagnosis alone [69] and it is therefore possible that some instances of seizure reduction or cessation would have occurred whether or not the intervention was delivered. Taken in combination with other factors such as highly specific or poorly defined source populations, conclusions regarding the

effectiveness of psychological interventions on seizure frequency and HRQoL in adults diagnosed with NEAD cannot be made based on studies included in this review. Nevertheless, the consistency of positive findings across studies point to this being a promising area for future research.

5.1. Limitations of the current review

A multi-component search strategy was used to conduct thorough searches of four multi-disciplinary databases in order to capture relevant studies. The risk of relevant research being overlooked is nevertheless inherent with any literature review. This risk may have been amplified in the present review since studies investigating seizure frequency or QoL as either primary, secondary or exploratory outcomes were considered for inclusion. This broad approach was chosen because initial scoping searches suggested there was limited research in the area. Nevertheless, secondary and exploratory variables are often not included in study titles or abstracts and relevant articles may, therefore, have been missed during the screening process. A future replication could screen articles by method section rather than by title and abstract to address the risk of relevant studies being overlooked.

Subjective bias is necessarily introduced when study identification, appraisal and synthesis is completed independently. Having another reviewer involved in these processes would have improved the reliability of the present review. In lieu of this practice, the first author developed clear inclusion and exclusion criteria, rubrics for scoring on the quality appraisal tool and sought supervision from a reference librarian and research supervisor. Risk of subjective bias nevertheless remains significant.

5.2. Recommendations for future research

As with previous reviews in the area, this review's conclusions regarding the effectiveness of psychological interventions for individuals with NEAD are limited by the quality of included studies. Future research should prioritise methodological rigour. In particular, future studies should be adequately

powered, include detailed sample characteristics, employ appropriate control groups and provide clearer, more complete information about both recruitment and attrition. Clear descriptions of study samples are paramount given the current theoretical viewpoint that NEAD is not a single, freestanding diagnostic entity but a heterogeneous condition with multiple potential predisposing and precipitating factors [23]. It is essential that study authors describe sample characteristics such as, time since diagnosis, history of trauma, wider mental health, concurrent epilepsy and previous knowledge/experience of seizures. This will allow more nuanced investigation of whether certain psychological interventions are best suited to particular presentations of NEAD. Although results are not yet published, a well-powered multi-site randomised controlled trial of CBT for individuals with NEAD has recently been completed and is anticipated to satisfy these recommendations for future research [70].

The research base would benefit from consensus on the measurement of seizure frequency and HRQoL to facilitate comparison and meta-analysis. At present, HRQoL measures designed for individuals with epilepsy are frequently used in NEAD research. Such measures have not been validated in this population [36] and contain irrelevant items such as those related to epilepsy medication. Future research should investigate the validity of such scales when used with individuals with NEAD or ideally, develop and validate a custom measure of HRQoL in NEAD [36]. Meantime, the reporting of QoL data should be standardised. In keeping with a recent systematic review which identified widespread inconsistency in the reporting of SF36 outcome data [71], all three studies which used the SF36, reported it differently. De Barros et al. [57] reported outcome data for all eight subscales, Metin et al. [60] provided data only for the subscale upon which they detected statistically significant change, and Mayor et al. [62] instead reported the physical and mental health component summary scores calculated using the eight subscales. Such disparity in reporting and analysis precludes meaningful comparison across studies. Some researchers have recommended that, for transparency, all research using the SF36 should report all eight SF36 subscales in addition to the two component summary scores [71]. In relation to seizure frequency,

techniques such as text reminders [72] or enlisting family members to assist in completing seizure logs should be considered to ensure self-reported seizure frequency is as accurate as possible in future studies.

If future research confirms this review's preliminary indication that psychoeducation-based interventions do not have the same effect on seizure frequency and QoL as longer-term psychological interventions, psychoeducational interventions should be considered separately in future research and reviews. Indeed, as the amount of research into NEAD continues to increase, it will be important to consider different therapeutic approaches (e.g. CBT, DBT, psychoanalysis) separately so findings can be refined. Continuing to group psychological therapies into a single entity will mask more nuanced effects between interventions. The effect of combination psychological and pharmacological intervention also merits future study.

Included studies featured other psychological outcomes in addition to QoL including low mood [17,53,57], anxiety [53,57,60], symptoms of trauma [17,53] and dissociation [53]. A broader review synthesising the effects of psychological interventions on other psychological outcomes for people with NEAD was outside the scope of this review. Such a review would nevertheless be beneficial in summarising current best available evidence for clinicians and researchers. In particular, it would be helpful to summarise outcomes in relation to depression and dissociation given these factors have been found to correlate with QoL in NEAD [36]. This would allow research to go beyond the traditional medical assessment of seizure frequency and severity and further develop psychological understanding of NEAD.

5.3. Clinical implications

Results require replication from more methodologically robust studies. The current evidence base does, however, suggest multiple forms of psychological therapy may be of benefit in improving QoL, reducing seizure frequency and potentially even enabling some individuals with NEAD to achieve seizure

freedom. Psychological interventions may be of benefit to people with NEAD and prove helpful in improving their QoL and reducing seizures. If corroborated by future research, review findings could inform the development of intervention pathways for people diagnosed with NEAD. For example, psychoeducation could be recommended to increase understanding and develop readiness for psychological therapy before longer-term psychological intervention is embarked upon. Such intervention pathways would hopefully assist with the sense of "post-diagnostic limbo" and confusion reportedly experienced by individuals with NEAD immediately post- diagnosis [15]. Finally, NEAD sits at the intersection of physical and mental health services and medical teams typically have little psychology presence. Introducing Clinical Psychologists with relevant experience into multidisciplinary teams in epilepsy and neuropsychiatric units may assist the process of formulating individual clients' experiences and directing them to appropriate psychological intervention.

6. Conclusion

This review examined the effect of psychological interventions on QoL and/or seizure frequency outcomes in adults diagnosed with NEAD. With the exception of studies delivering psychoeducation, all intervention studies reported improvements in seizure frequency and QoL, where measured. Included studies were, however, diverse in terms of design and quality, and reliable conclusions regarding the effectiveness of psychological interventions in improving seizure frequency and QoL cannot be drawn. Nevertheless, the consistency with which studies reported positive findings is promising in suggesting that a range of psychological interventions might be beneficial for individuals with NEAD. The recommendations of previous reviews are echoed: future research must prioritise sound methodological design in order that the effects of psychological intervention for NEAD can be better understood and used to inform care pathways. Future research should investigate the effects of psychological intervention on psychological outcome measures such as quality of life, in addition to seizure frequency, so that clinically meaningful targets for intervention can be identified.

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Appendices

Appendix A- Guidelines for authors, Epilepsy and Behavior

These guidelines have been condensed. Full guidelines for authors can be found at: https://www.elsevier.com/journals/epilepsy-and-behavior/1525-5050/guide-for-authors

Article structure

Subdivision - numbered sections
Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Abstract
A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Introduction
State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods
Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Results
Results should be clear and concise.

Discussion
The **Discussion** section should explore the significance of the results of the work, not repeat them. **Results** and **Discussion** should be separate and may be organized into subheadings. Avoid extensive citations and discussion of published literature.

Conclusions
The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Reference style

Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.
List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:
Reference to a journal publication:
[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. J Sci Commun 2010;163:51–9. https://doi.org/10.1016/j.Sc.2010.00372.
Reference to a journal publication with an article number:
[2] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. Heliyon. 2018;19:e00205. https://doi.org/10.1016/j.heliyon.2018.e00205

Reference to a book:
[3] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.
Reference to a chapter in an edited book:
[4] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:
[5] Cancer Research UK. Cancer statistics reports for the UK, http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/; 2003 [accessed 13 March 2003].

Reference to a dataset:
[dataset] [6] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for

Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015. https://doi.org/10.17632/xwj98nb39r.1.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

Journal abbreviations source

Journal names should be abbreviated according to the List of Title Word Abbreviations.

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Articles should make no assumptions about the beliefs or commitments of any reader, should contain nothing which might imply that one individual is superior to another on the grounds of race, sex, culture or any other characteristic, and should use inclusive language throughout. Authors should ensure that writing is free from bias, for instance by using 'he or she', 'his/her' instead of 'he' or 'his', and by making use of job titles that are free of stereotyping (e.g. 'chairperson' instead of 'chairman' and 'flight attendant' instead of 'stewardess').

Appendix B- Example completed data extraction form

Study	Chen et al. [55]
Country	• USA
Years Data collected	• June 2011- October 2012
Journal	• Epilepsia (Peer Reviewed)
Aim:	• "to evaluate therapeutic efficacy upon augmenting the initial communication of the diagnosis with brief group psychoeducation within 4 weeks of diagnosis"
Design:	• Pilot RCT • Measures completed at baseline, immediately following completion of intervention and three months following completion of intervention. • 65% completed intervention within ~3months; 35% ~5 months of diagnosis • Control group completed measures at baseline, ~3 months after diagnosis and ~6 months after diagnosis.
Randomisation method:	• Consecutive in the order of enrolment. Computer generated random number. Even= intervention. Odd= control
Setting	• Veterans Medical Centre
Sample	• 107 Veterans who had consecutively received a diagnosis of NEAD in the past four weeks.
Groups equivalent	• No difference in baseline characteristics
Population characteristics:	Intervention group (n=34): • Veterans • Age: 50.76 (SD 12.27) • Female: 26.5% • Married: 55.9% • Education: 12.91 years (sd=1.68) • Employed: 20.6% • Disability related benefits:52.9% • No. of psychiatric diagnoses: 2 (sd=1.13) • Concurrent therapy: 26.5% • PTSD: 35% • GAF: 58.13 (8.16) • Daily seizures: 9 (26.5%) • Weekly seizures: 16 (47%) • Monthly seizures: 7 (20%) • Rare: fewer than three seizures per year: 2 (5.9%) • Mean duration: 106 months (115.92)

	• BDI: 21.36
Confounds assessed	Exclusion: • Mini-Mental State Exam Score< 25 • Non-commutable distance to setting • Diagnosis of epilepsy
VEEG confirmed diagnosis?	• Yes
Comorbid epilepsy?	• No. Excluded.
Attrition	• 107 identified • 36 excluded (exclusion criteria) • 7 declined participation • 64 enrolled in study • 34 randomised to intervention, 30 randomised to control group • 14 intervention & 9 control “unable to complete at least one survey of outcome measures” • N= 20 (intervention) and n=23 (control) included in analyses. No difference in baseline characteristics between completers and non-completers
Intervention	• 3 x 1.5 h monthly group psychoeducation sessions • Significant others encouraged to attend 1. Lecture based format- understanding NEAD 2. Support group format- underlying emotional causes, triggers and stress management, sharing strategies 3. Support group format- Distress tolerance, stress management. • Attendance- 3-10 per group (excluding family members)
Intervention delivered by:	• Neurologist or neurology nurse practitioner
Training:	• Prior experience of psychoeducation and NEAD
Fidelity	• Therapist fidelity not measured
Control	• Routine seizure clinic follow-up at ~3 months (3-5 months) and ~6 months • Emphasis on conceptual iteration of psychological origins of NEAD. Referrals and medication withdrawal as appropriate.
Follow-up	• ~3 months following completion of intervention.
Primary Outcome	• Work and Social Adjustment Scale (WSAS) • Participant perceptions of improvement in seizure frequency and intensity (Likert 1-5) Encouraged to

	consult seizure logs when rating.
Secondary Outcome	• NEAD- related Emergency room visits or hospitalization • Any new disabling medically unexplained symptoms • Participant ratings of NEAD knowledge and perception
Statistical analysis	• Per-protocol analysis (completers only) • Mann-Whitney-U (between groups) for Likert questions • Chi squared or Fisher's exact test for categorical variables • Unpaired T test for continuous variables (parametric) • Repeated measures ANOVA for WSAS scores. Within subject factor: time point; between subject factor: group
Key Findings	• WSAS significantly improved in intervention group but not control to 6m follow-up. • No significant effect on participant ratings of NEAD frequency (5 categories) at either follow-up point. • Over course of follow-up, 1 participant from intervention group and 5 from control group required hospitalization (NS) • Changes in perceptions of NEAD in intervention group • No difference in new medically unexplained symptoms, initiation of psychotherapy or psychotropic meds.
Power	• Calculation not included. "may not be sufficiently powered"
Effect Size	• N/A
Conclusions	• "Patients who completed the intervention demonstrated significant improvement in WSAS scores, reflecting improvement in important areas of functioning." • "multicentre studies would strengthen the statistical power and generalizability of the intervention outcome" • "Although patients did not enjoy significant seizure reduction, we believe they did achieve meaningful functional improvement to allow for better engagement with life and future gains."
Discussion Points	• Groups factors such as increased legitimacy of strategies endorsed by peers, may have influenced outcome. • Inclusion of Family in group. What is active component?
Main weakness	• Made seizure frequency into categorical rather than continuous variable (e.g. one to several seizures per week, one to several seizures per month or fewer than three seizures per year) at baseline and change measured with Likert ratings rather than frequency counts.

Appendix C- Modified Downs- Black Checklist [48]

Modified Downs-Black Checklist (1998)

Asterix's (*) mark items where adaptations have been made to scoring advised in the original Downs-Black Modified Checklist. Text in green represents scoring guidelines added by the current author to enable consistent scoring across studies in the present review. 'Follow-up' was operationalised as the last measurement point in a design across all questions.

Item	Criterion	Rating			Notes/ Justification
	Reporting				
1	Is the hypothesis/aim/objective of the study clearly described?	No: 0	Yes: 1		
2	Are the main outcomes to be measured clearly described in the introduction or methods section? *No If the main outcomes are first mentioned in the Results section*	No: 0	Yes: 1		
3	Are the characteristics of the patients included in the study clearly described? *In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.*	No: 0	Yes: 1		

4	Are the interventions of interest clearly described? *Treatments and placebo (where relevant) that are to be compared should be clearly described.*	No: 0	Yes: 1		
5	Are the distributions of principal confounders in each group of subjects to be compared clearly described? *A list of principal confounders is provided.* *-Distributions of confounders must be listed even if there is only one group.* *-Yes: Must include information re. time since first seizure, time since diagnosis, concurrent epilepsy(Y/N), VEEG confirmed diagnosis (Y/N), current mental health difficulties.* *-Partially: 3 or more of the above confounders described.*	No: 0	Partially: 1	Yes: 2	
6	Are the main findings of the study clearly described? *Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).*	No: 0	Yes: 1		
7	Does the study provide estimates of the random variability in the data for the main outcomes? *In non-normally distributed data, the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.*	No: 0	Yes: 1		

8	Have all important adverse events that may be a consequence of the intervention been reported? *This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).*	No: 0	Yes: 1		
9	Have the characteristics of patients lost to follow-up been described? *This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered nowhere a study does not report the number of patients lost to follow-up.* *-Was the number of participants lost to follow-up described?*	No: 0	Yes 1		
10	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	No: 0	Yes: 1		

<u>External Validity</u> All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.					
11	Were the subjects asked to participate in the study representative of the entire population from which they were recruited? *The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.*	Unable to determine: 0	No: 0	Yes: 1	
12	Were those subjects who were prepared to participate representative of the entire population from which they were recruited? *The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.*	Unable to determine: 0	No: 0	Yes: 1	

13	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive? *For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.*	Unable to determine: 0	No: 0	Yes: 1	
Internal validity- bias					
14	Was an attempt made to blind study subjects to the intervention they have received? *For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.*	Unable to determine: 0	No: 0	Yes: 1	
15	Was an attempt made to blind those measuring the main outcomes of the intervention?	Unable to determine: 0	No: 0	Yes: 1	

16	If any of the results of the study were based on “data dredging”, was this made clear? *Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.*	Unable to determine: 0	No: 0	Yes: 1	
17	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? *Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.*	Unable to determine: 0	No: 0	Yes: 1	
18*	Were the statistical tests used to assess the main outcomes appropriate? *The statistical techniques used must be appropriate to the data. For example, nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.* *-Partially: Tests are appropriate for one of the two focal outcome measures. Or, further analysis would have been beneficial.*	Unable to determine: 0 No: 0	Partially: 1	Yes: 2	

19	Was compliance with the intervention/s reliable? *Where there was non-compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes*.	Unable to determine: 0	No: 0	Yes: 1	
20*	Were the main outcome measures used accurate (valid and reliable)? *For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.* *-Partially: Outcome measurement was appropriate for one of the two focal outcome measures. Or, further attempts to improve validity would have been beneficial.*	No/ Unable to determine: 0	Partially: 1	Yes: 2	
Internal Validity- Confounding (Selection Bias)					
21	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? *For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case control studies where there is no information concerning the source of patients included in the study.*	Unable to determine: 0	No: 0	Yes: 1	

22	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time? *For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.*	Unable to determine: 0	No: 0	Yes: 1	
23	Were study subjects randomised to intervention groups? Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.	Unable to determine: 0	No: 0	Yes: 1	
24	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable? *All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.*	Unable to determine: 0	No: 0	Yes: 1	

25	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn? *This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.*	Unable to determine: 0	No: 0	Yes: 1	
26	Were losses of patients to follow-up taken into account? *If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.* *-Were the characteristics of those lost to follow-up described/ compared to completers?*	Unable to determine: 0	No: 0	Yes: 1	
Power					
27*	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? -If power calculation not present- rate unable to determine	Unable to determine: 0	No: 0	Yes: 1	

Domains (score available-full checklist)	Total (/30)	Reporting (/11)	External Validity (3)	Internal Validity-bias (9)	Internal validity-confounding (/6)	Power (/1)
Score available from applicable items						
Score						

Appendix D: Table 3- ***Quality ratings awarded to included studies using the Modified Downs-Black checklist*** [42]

Study	Domains (Score Available)					Total	
	Reporting (11)	External Validity (3)	Internal Validity-bias (9)	Internal validity-confounding (6)	Power (1)	Score	%
Chen et al. [55]	9	3	2	6	0	20/30	66.7%
De Barros et al. [57]	8	2	5	2	0	17/30	56.7%
La France et al. [53]	8	0	3	2	0	13/30	43.3%
Metin et al. [60]	6	0	4	2	0	12/30	40%
Thompson et al. [56]	7	1	5	2	0	15/30	50%
Tolchin et al. [54]	9	1	5	5	0	21/30	70%
Mayor et al. [62]	7	1	4	0	0	12/30	40%
Tolchin et al. [58]	9	1	3	2	0	15/26	57.7%
De Oliveira Santos et al. [59]	7	1	4	0/2	0	12/26	46.2%
Myers et al. [17]	7	0	2	0/2	0	9/26	34.6%
Bullock et al. [61]	10	0	4	2/2	0	16/26	61.5%

Appendix E: Table 4- ***Attrition details in included studies.***

Study	Invited (n)	Enrolled (n)	Commenced (n)	Completed Intervention (n)	Definition of "completion"
Bullock et al. (2015) [61]	22	21	20	19 (Range 1-5 modules)	Attended at least one of three repeating 8-10 session skills group modules
Chen et al. (2014) [55]	71	64	26	20	Attended all three sessions
De Barros et al. (2018) [57]	70	47	47	47	Attended all 8 sessions
de Oliveira Santos et al. (2014) [59]	48	37	37	19	Attended 48 sessions
La France et al. (2013) [53]	81	38	Data not available	34	No definition provided
Mayor et al. (2013) [62]	38	29	20	17	Attended at least 3/4 sessions
Metin et al. (2013) [60]	Data not available	13	Data not available	9	Attended >75% of intervention
Myers et al. (2017) [17]	19	18	18	16	No definition provided
Thompson et al. (2012) [56]	22	19	19	19	Completed the single session intervention
Tolchin et al. (2019a) [58]	N/A	105	Data not available	72	Attended >8/12 sessions.
Tolchin et al. (2019b) [54]	62	60	57	26	Attended >8/12 sessions.

Paper Two: Empirical paper

The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD): an interpretive phenomenological analysis.

Word count: 7956

Target journal: Qualitative Health Research
(see Appendix A for submission guidelines)

Abstract

Non-Epileptic Attack Disorder (NEAD) is the most commonly diagnosed functional neurological condition worldwide. The families of those diagnosed with NEAD have received little focus in research to date. This study aimed to explore the experiences of carers supporting an adult family member diagnosed with NEAD. Eight family carers (four spouses and four mothers) took part in semi-structured interviews over Skype and interview data was analysed using Interpretive Phenomenological Analysis. Three superordinate and ten subordinate themes were developed from the data. Superordinate themes related to: the personal impact of caring, navigating the reactions of others, and the importance of having an explanatory framework for seizures. Relationships with professionals that were experienced as respectful and collaborative, and the provision of information which developed carers' biopsychosocial understanding of NEAD, facilitated changes in caring approach and carer wellbeing. Such support was, however, reportedly rare and difficult to access. Clinical opportunities to support both individuals with NEAD and their carers are discussed.

Introduction

Non-Epileptic Attack Disorder (NEAD) is characterised by episodes which outwardly resemble epileptic seizures yet have no discernible origin in underlying electrical brain activity (Lesser, 1996). Instead, non-epileptic seizures are conceptualised from a biopsychosocial perspective, and hypothesised to result from the interaction of various psychological, social and neurobiological underpinnings, dependent on individual circumstances (Brown & Reuber, 2016; Szaflarski et al., 2018). In some instances, for example, non-epileptic seizures may be understood as a dissociative response to memories of trauma (Myers et al., 2017), or an automatic stress reaction akin to fight, flight and freeze responses that serves to regulate arousal (Baslet, 2010). A recent systematic review has, however, highlighted that uncertainty and stigmatising views of NEAD are common amongst healthcare professionals, especially in non-specialist settings (Rawlings & Reuber, 2018). One included study, for example, reported that 50% of a sample of 115 nurses who had encountered NEAD believed seizures to be “fake” and under voluntary control (Sahaya et al., 2012).

There is currently no standardised diagnostic and treatment pathway for NEAD (Gasparini et al., 2019), with one study reporting average delays of seven years between symptom onset and diagnosis (Duncan et al., 2010). Psychological therapy is supported as the treatment of choice by healthcare professionals working with seizure disorders (Mayor et al., 2011) and a systematic review of psychological intervention studies reported seizure reductions of 50% or greater in 82.5% of those completing psychological therapy for NEAD (Carlson and Perry, 2017). Individuals diagnosed with NEAD themselves often, however, hold organic explanations of their seizures and can be reluctant to engage with psychological therapy (Rawlings & Reuber, 2016). A sense of being unsupported following diagnosis is commonplace; as is a sense of isolation, reduced freedom, independence and privacy (Fairclough et al., 2013). Individuals diagnosed with NEAD are also likely to have been diagnosed with mood disorder, personality disorder, Post-Traumatic Stress Disorder (PTSD) or another anxiety diagnosis (Bodde et al., 2009).

The families of those experiencing seizures often provide emotional support during the aforementioned route to diagnosis and assist in reducing the risk of personal injury during seizures (Saada et al., 2015). They may find themselves more highly depended upon for practical support with activities of daily living such as cooking and bathing; as well as driving if the if the person experiencing seizures has had to surrender their driving license (Wardrope et al., 2019). Research across health conditions has consistently found that caring responsibilities can negatively affect family carers' physical and psychological health (Carers UK, 2019), and multiple recent policy directives encourage exploration of carer experience, and their inclusion as equal partners in care (e.g. Department of Health and Social Care [DoH], 2018; National Institute for Health and Care Excellence [NICE], 2020). The small amount of extant quantitative research conducted with those who care for a family member with NEAD has compared them to those who care for a family member with epilepsy. Although both groups have been found to have an equivalently low overall Quality of Life (QoL) (Karakis et al., 2014), carers for family members diagnosed with NEAD have been found to be significantly more likely to experience clinical levels of depression than carers for family members with epilepsy (Wardrope et al., 2019).

To the best of the author's knowledge, published qualitative research has, to date, focused on exploring the experiences of parents caring for children diagnosed with NEAD. McWilliams et al. (2016) conducted focus groups and telephone interviews with 10 young people (6- 19 years) with NEAD and 29 of their family members. Thematic analysis of interview data indicated that family members commonly felt upset, confused and afraid during seizures; many remaining unclear about the diagnosis and viewing understanding as a prerequisite for their child's recovery. Similar themes were mirrored in the findings of Hulgaard et al. (2019) who interviewed parents of eleven children (aged 11-16) with a range of functional health conditions, including four children with a diagnosis of NEAD. These parents also described the emotional challenge of feeling their parenting skills were being called into question and that they were implicated in the development of their child's seizures. Caution should be exercised in generalising the results of research conducted with

carers of children with NEAD to those caring for adults. A recent systematic review identified that children are less likely to experience motor symptoms during seizures than adults and are also more likely to achieve seizure freedom (Reilly et al., 2013). Such factors may result in different caring experiences and challenges, depending upon the age of the person being cared for.

Illness perceptions are dynamic internal models consisting of preconceptions, assumptions and expectations concerning a medical condition (Leventhal et al., 1997). The illness perceptions of caregivers can influence the health outcomes of those they are caring for. Kaptein et al. (2007), for example, found that more realistic carer perceptions of the chronic course of their family member's Huntington's disease were associated with increased vitality in the person being cared for (as measured using the Medical Outcome Study 36-item Short Form Health Survey [SF36]). Research into illness perceptions in NEAD has found that carers are significantly more likely than those experiencing NEAD to accept stress and other psychological factors as contributing to seizures (Whitehead et al., 2015; Reuber et al., 2011). Carers could potentially, therefore, have an influential role in helping their family member consider engaging with empirically supported psychological therapy (Carlson & Perry, 2017; Martlew et al., 2014).

The wellbeing of those caring for an adult family member diagnosed with NEAD has been understudied in research to date, as have the potential indirect benefits of improving carer wellbeing for those being cared for. Parallel research with epilepsy carers, for example, found that carer QoL predicted the QoL of the person with epilepsy (Mahrer-Imhof et al., 2013). Likewise, higher levels of carer anxiety and depression have been found to correlate with lower QoL in family members with epilepsy (Zhu et al., 2019).

As the first qualitative study to explore the experiences of family carers for adults diagnosed with NEAD, this study aims to give voice to carers and develop an understanding of their experiences. It aims to answer the research question: What are the experiences of family carers supporting an adult family member diagnosed with Non-Epileptic Attack Disorder? This is considered important so that any support needs of the families of those diagnosed with NEAD can be accounted for in any future best practice guidelines.

Method

Design

The study used a qualitative design with online recruitment and remote semi-structured interviews. Data were analysed using Interpretive Phenomenological Analysis (IPA). IPA complemented the aim of the study because of its central focus on the detailed exploration of how people perceive and understand particular experiences (Smith & Eatough, 2016). There is an acknowledgement in IPA that personal meaning is not directly accessible, and analysis is therefore seen to involve a two-stage interpretive process; the researcher tries to make sense of how the participant makes sense of their experience. For this reason, IPA requires that the interpretive stance of the researcher is explicitly stated and considered throughout analysis to limit risk of bias. This makes it a useful approach for research with stigmatised medical conditions such as NEAD (e.g. Chronic Fatigue: Catchpole & Garip, 2019; fibromyalgia: Rodham et al., 2010).

Recruitment

The study was advertised on Facebook and Twitter between October and December 2019 (Appendix B). Permission was sought from administrators of local and national NEAD support groups and organisations to display the study advert on their social media channels. Participants were purposefully recruited according to self-identifying as the main carer for an adult family member (aged above 18 years) who had been diagnosed with NEAD by a medical professional. To ensure homogeneity within the sample, participants were also required to live in the United Kingdom, to live with the person they cared for (or provide support at least five days a week) and to be supporting someone who had been diagnosed with NEAD for over one year and did not also have a diagnosis of epilepsy. A sample size of six–eight participants has been suggested as an optimal number in Interpretive Phenomenological Analysis (IPA) to allow examination of similarities and differences between cases whilst preserving depth of analysis (Smith & Eatough, 2016). Recruitment continued until eight participants had been recruited. Subsequent volunteers were thanked

for their interest and provided with a copy of the study information sheet which contained sources of further information and support (Appendix C).

Procedure

Individuals who contacted the researcher to express interest were emailed the study information sheet (Appendix C) and screening questions (Appendix D) to determine eligibility. Participants who met inclusion criteria and gave written informed consent (Appendix E) to participate then arranged a convenient time to take part in a semi-structured interview. To facilitate participation, interviews could be completed either in person at the host institution, via Skype or via telephone. All participants elected to complete interviews via Skype and interviews lasted an average of one hour and eighteen minutes (range: 45 -102 minutes). Interviews began with a series of demographic questions covering topics such as carer age and length of time in caring role (Appendix F). Such data was collected so that the sample could be accurately described and situated amongst current literature. The interview proper followed an hourglass structure (McConnell-Henry et al., 2011) with sensitive items requiring greater personal reflection sandwiched between items that lent themselves towards more descriptive answers (Appendix F). In line with IPA methodology, the interview schedule was treated as a guide and not a prescribed structure; interviews followed the course set by participants wherever the topic of discussion remained relevant to the research aim. At the end of each interview, participants were provided with a debrief document via email (Appendix G) and offered the opportunity to ask any additional questions. Interviews were recorded and transcribed verbatim by the researcher.

Ethical considerations

Ethical approval for the study was granted by Staffordshire University Ethics Committee (Appendix H). Participants provided written consent for participation, including consent for the use of direct quotes from their interviews in this article. In order to maintain anonymity, participant identifiable information was removed,

and pseudonyms used from the point of transcription. Client location and emergency contact details were obtained at the start of each interview, following the Kasket (2009) risk protocol for remote interviews (Appendix I). Participants were encouraged to participate in the study at a time and location where they could ensure privacy, to facilitate open discussion of their experiences.

Participants

Seven female carers and one male carer, aged between 28 and 67 years, participated in the research. Four were caring for their spouses, and four for adult daughters. Most had supported their family member since the onset of their seizures, with two carers supporting spouses whose seizures pre-dated their relationship. All carers lived with the person they were supporting, estimating an average of twenty hours per week spent caring. One carer advised she was currently not actively caring for her wife as she was experiencing a seizure free period. Several carers described health difficulties of their own including anxiety and depression. Carer characteristics are shown in Table 1.

Participants reported that the family members they cared for had experienced seizures for an average of four years (range: 16-32 months) and had been diagnosed with NEAD for an average of two and a half years (range: 14-132 months). An average of three seizures per week (range:0-25) were reported, with most recent seizures having occurred between one day and five months ago. Family members being cared for were reported to experience a range of other concurrent health conditions including anxiety, Post-Traumatic Stress Disorder (PTSD), depression, psychosis, functional movement disorder and Autism Spectrum Disorder (ASD).

Table 1: *Summary of carer characteristics*

Participant Pseudonym	Relationship to person with NEAD	Age of carer	Years of care provided	Estimated hours spent caring per week	Health Difficulties
Rachel	Mother	40	4	20	Anxiety
Gemma	Wife	44	5	14	Hearing impairment. Back problems.
Naisha	Wife	29	4	0	Depression
Carol	Mother	62	1	N/A*	-
Annika	Mother	67	2	60	-
Jeanette	Mother	62	4	32	Anxiety
Millie	Wife	28	6	2	-
Ian	Husband	41	4	35	Anxiety/ Depression

*Participant advised it was not possible to estimate hours spent caring. Response: "most of the time"

Analysis

Transcripts were analysed in turn following the guidelines of Smith et al. (2009). The first stage of analysis involved the close reading and re-reading of each transcript. Initial observations relating to descriptive content, linguistic features and potential implied meanings were then noted in the right-hand margin of the transcript. From these initial notes, emergent themes were developed and recorded in the left-hand margin (Appendix J). Once all transcripts had been considered in this way, themes emerging in later transcripts were checked against earlier transcripts and any revisions or additions to initial themes noted. The next step involved grouping emergent themes into clusters and considering relationships between them for each case: emergent themes were first compiled into chronological lists and then grouped for similarity (Appendix K). Analysis moved to the group level once this process had been completed for all cases. Themes were compared across cases (Appendix L) and related themes grouped and revised under higher order labels (Appendix M) to produce a final list of superordinate and subordinate themes (Table 2).

Rigour

The primary researcher performed the analysis, with an experienced IPA researcher independently analysing one interview transcript and contributing to discussions of final theme arrangement. This process was viewed as a coherence and credibility check rather than an attempt to establish inter-rater reliability, in line with the interpretive nature of IPA and its rejection of positivist assumptions of a singular, objective truth.

Epistemological position and reflexivity

The researcher holds a constructionist-interpretivist epistemological position, viewing meaning as something which is socially constructed rather than objectively discoverable (Lyons & Coyle, 2016). This position allows overt acknowledgement of the fact that the researcher is part of the social world, and her own experiences and beliefs will therefore influence her interpretation.

The researcher is a Clinical Psychologist in training with no personal connection to NEAD. She does however have close family members who occupy caring roles and a close friend who describes having been traumatised through witnessing her sister's epileptic seizures as a child. These personal connections resulted in an early expectation that the caring role would be inherently challenging. This expectation changed as interview data emerged to the contrary.

The researcher made reflective notes throughout the interview and analysis process to document her interaction with the data (Appendix N). Noting and considering the origins of emotional reactions to the interview data allowed for consideration of their potential influence on interpretation, increasing the transparency of the analysis.

Results

Three superordinate themes and ten subordinate themes were derived from analysis of the interview data (Table 2). Superordinate themes related to 1.) the personal impact of caring 2.) navigating the reactions of others and 3.) the importance of having an explanatory framework for seizures. Additional supporting quotes for each theme can be found in Appendix O.

Table 2: *Themes and subthemes derived from interview data*

Theme	Subthemes
1. The personal impact of caring	1.1. 'I thought I'd be living a different life' 1.2. 'I need to make sure you're safe' 1.3. 'Head down, getting on and doing what needs to be done'
2. Navigating the reactions of others	2.1. 'Getting pushed from pillar to post and back again' 2.2. 'Lived-in experience can be discounted' 2.3. 'People don't know what it is' 2.4. 'Knowing I'm not the only person going through this, it helps'
3. The importance of having an explanatory framework for seizures	3.1. 'There were no answers, no real answers' 3.2. 'It's much easier to deal with if you have a story you can tell' 3.3. 'A whole different way of approaching the seizures'

Theme one: The personal impact of caring

Carers described how wide-ranging areas of their lives, including their identity, occupation, independence and relationships had been impacted by their caring role, and largely saw this impact as inevitable. There was a clear prioritisation of the needs of the family member being cared for over carers' own needs, especially in the early phases of caring.

1.1 'I thought I'd be living a different life'

All but the two wives who were aware of their partners' seizures before entering into their relationships reported that the onset of their family members' seizures changed the anticipated course of their lives. Most carers had to give up or reduce their work hours for their caring responsibilities and experienced difficulties in adjusting to this change. For example, Ian described the shock of being informed that he did not meet criteria to be considered "*gainfully self-employed*" by the Department of Work and Pensions (DWP) and how this ultimately caused him to re-evaluate his identity:

"It's been a slow process that I've… started to, or got to the point of, yes, you know, when people say 'oh what do you do?' it was always like: 'well, I'm a plumber but I also care for my wife' and it's now like: 'I'm a carer for my wife and I also do a bit of plumbing if I've got time.'" (Ian).

Parental carers spoke of expecting to have greater amounts of freedom, privacy and quality time with their partners at this stage of their daughters' lives. Carers often described feeling that their lives had to be put on hold while their family member was prioritised. Whilst this was reportedly experienced as being understandable, it was also experienced as painful. Some carers also described feeling guilty about their desires for freedom, independence and privacy:

"I know it's a selfish point of view really and it is selfish, y'know, she's my child but I honestly believed she'd be 19 driving a car and I'd probably be worried about her crawling in at 4 o'clock in the morning, y'know, after a few drinks and

the reality is that she would have grown out of that. And I just think, we could be still doing this [caring] in another twenty years." (Rachel).

Carers reported difficulty adjusting to changes in their identity and the disparity between their current, and previously anticipated, realities.

1.2 'I need to make sure you're safe'

Carers unanimously reported feeling responsible for keeping their family member safe. For parental caregivers, there was a sense of being duty-bound to continue in parental roles beyond the age where they expected such responsibilities would lessen, and feeling that relationships had been arrested in their development from a child-mother dynamic to an adult child-mother dynamic. Rachel likened caring for her young adult daughter to "*a never-ending hamster wheel*", reminiscent of the high level of care need typically associated with young children. Spousal carers also reported having to be cautious of falling into an overprotective role in their relationships. Gemma reported she initially tried to create a stress- and responsibility-free life for her partner but that this had significant unexpected consequences; she thought this approach had made her husband feel "*useless"* and had ultimately contributed to him attempting to end his life:

"I think really we needed Colin to hit rock bottom last year to build things back up and to work out, well actually, although we thought we were doing the best, we'd gone too far with things and we'd just stripped everything away… and that was no good because neither of us felt appreciated or any use." (Gemma).

Mothers thought they were sometimes resented by their daughters for the way in which trying to ensure their safety restricted their independence:

"She sometimes says: 'You're being too controlling' or: 'I'm not being independent enough' or something and I try, you know, I try to explain: 'I need to make sure you're safe." (Annika).

In contrast to the wide-ranging negative impacts discussed, most carers also described how they had experienced increased closeness in their relationship

with their family member through supporting them with their seizures. Spouses, in particular, described how the caring role had facilitated open communication, reciprocal comfort with asking for help and a sense of being united against a common enemy:

"We had to have all these horrible conversations quite early on and it meant that we could be quite open with each other moving forwards. So now I know… he has to talk to me about his mental health so that I can help him keep a lid on it and I guess that's helped me in opening up to him as well" (Millie).

The two participants who met their partners knowing they had NEAD also reported experiencing a sense of purpose and personal reward through caring for their partners and seeing improvements in their seizures and mental health. Indeed, Naisha described difficulties adjusting to the loss of her caring role following a reduction in her wife's seizures:

"I felt needed before… erm… because she needed that company and she needed that support, erm and then she, sort of, became quite independent and it felt like quite a big change." (Naisha).

Both parent and spousal caregivers described the difficulty of balancing their desire to protect their family member with their family member's desire for independence.

1.3 'Head down, getting on and doing what needs to be done'

Carers shared that they had rarely reflected on their role and the personal emotional impact of supporting their loved one, especially in the earlier stages of their caregiving careers. Several described being in a state of "*autopilot*" and some carers struggled to identify and describe the impact caring had upon them personally:

"It's… sad I suppose is the word, it's sad to see her like it." (Jeanette).

Some carers expressed doubts about the utility of focusing on the personal impact of caregiving, based on the belief that focusing on the inevitable difficulties of providing care would be of no benefit:

"There's no point letting it fester is there because you just have to think 'right this is how it is' and you find things to do and ways to cope and possibly make plans to try and improve the situation and you just, yea, you just have to keep going." (Carol).

Over time, some carers advised they had come to recognise the importance of meeting their own needs as well as those of their family member, although this was often reportedly difficult to implement:

"*I'm still learning on the, you know: 'Just take your foot off the gas occasionally and know that you can't do everything.'"* (Ian).

Carers reported either consciously or unconsciously avoiding thinking about the personal emotional impact of their caring role, especially in the early phases of caring.

Theme two: Navigating the reactions of others

All carers spoke of the significant challenge they faced in managing others' reactions to NEAD, whether that be the reactions of services, the general public or family and friends. Instances of support and understanding were memorable and meaningful.

2.1 'Getting pushed from pillar to post and back again'

Carers described varying paths to obtaining their family members' diagnoses, often punctuated with long waits and referral, discharge and re-referral to the same services. Carers were left with the impression that healthcare staff were not interested nor able to provide support:

"'This is above my pay grade', that's what he actually said to me. 'This is above my paygrade and I don't have any answers for you.'" (Rachel).

"I felt they were all… like she was being fobbed off by both sets of specialists and the neurologist said: 'Well we're not interested, it's not epilepsy, that's what we deal with.'" (Annika).

Experiences of feeling rejected by services reportedly left carers feeling alone in supporting their family member, with little sense of progress or direction:

"Three years have been wasted, we feel, we feel like we've been floating around in limbo land for three years." (Jeanette).

Several carers reported having to "*push*", be assertive and make use of personal contacts in order to access diagnosis and support, implying that services are not universally available as standard. Indeed, one carer reported having paid to obtain her daughter's diagnosis privately for fear of the impact a delay may have on her daughter's mental health:

"I have learnt that you have to be prepared to be quite assertive and direct with people and ask to change practitioners if necessary and just keep pushing." (Carol).

"If we'd had three or four months of hopelessness and not really knowing what was going on and: 'It might be this or it might be that', no, we might have lost her to be honest. You know, because her mental health was spiralling down at the same time as the seizures." (Carol).

The route to diagnosis was described as a challenging process which carers felt was their responsibility to navigate.

2.2 'Lived-in experience can be discounted'

Despite feeling the weight of responsibility for managing their loved ones' seizures, most carers who had experience of contact with services perceived themselves not to be valued nor believed by these services. Many reported

having become familiar with factors such as seizure triggers and typical duration over time. This experience, however, was reportedly rarely sought or trusted by health professionals. Carers felt underestimated and four carers independently identified listening and respecting the experience of carers as an area where services could improve:

"I just think that the lack of knowledge out there makes them think that families and the people who have the seizures can't understand it as well." (Gemma).

Carers described emotionally struggling with not feeling believed. Ian, who had held a longstanding position of responsibility in his local community before becoming a carer for his wife, described how difficult he had found feeling disbelieved during his application for carer's allowance on account of it challenging one of his central values:

"To sort of, you know, put everything in as plain and honest as you can in things like that [carer's allowance application] and then them to go: 'well actually, as far as we're concerned there's nothing wrong' it… it almost feels, it really feels like it calls your integrity and that into question." (Ian).

Carers also described being frustrated by not being able to attend appointments with their loved ones and relying on second-hand information to understand seizures and their management. The perception that few professionals encountered enquired about the impact of caring on the wider family was also described as frustrating:

"They didn't think they were very serious, yet they seemed to be completely ignoring how much they were impacting [our daughter's] life and our life." (Annika).

Carers described the significant emotional challenge of not feeling valued, believed nor included by services.

2.3 'People don't know what it is'

Carers spoke about their caring role being complicated by a widespread lack of awareness of NEAD both within and outside of medical settings. Managing public seizures was identified as being particularly challenging because of the need to fulfil a dual role: reassuring and informing members of the public at the same time as supporting their family member:

"If she has one in a public place, of course, everyone is always looking at her and: 'Ooh, what's going on?' and: 'Ooh, what do we need to do?'. Everybody's sort of flapping and getting anxious and panicking, you know: 'Do we need an ambulance?' and I'm saying: 'No it's alright, nothing bad will happen' and: 'Calm down.'" (Annika).

"I feel that part of my job is to try and educate people." (Annika).

It was also common for carers to report feeling vulnerable to judgement at such times. Parental caregivers were more likely to report this fear of public judgement:

"People are looking at me as if to say: 'Are you nuts, because how can you leave your child like this?'" (Rachel).

When not mistaken for epilepsy, carers described having to handle other negative public perceptions of NEAD including "*doesn't she just need a firm hand" (Carol),* "*is she just attention seeking?*" (Annika) and "*it's disgusting that [she's] drunk at nine o'clock in the morning."* (Rachel).

Competing opinions of NEAD were also reported to be common in services and employment contexts. Carers recounted hearing from medics, for example, "*it's nothing serious"* (Annika), from the DWP that their family member is *"fit for work"* (Rachel) and from colleagues and employers that they "*shouldn't be working*" and doing so is "*dangerous*" (Gemma).

Encountering competing, and often pejorative, views of NEAD was described as commonplace for carers and was experienced as adding an extra level of caring responsibility through positioning them as educators, advocates and sources of emotional support for their family members.

2.4 'Knowing I'm not the only person going through this, it helps'

It was common for carers to report a sense of solidarity from membership of support groups. Such groups were described as providing reassurance, access to research articles and new ideas of ways to support their family members. They were also reported to offer carers the opportunity for a more positive perspective of their own situation through comparison to those of others:

"There's people that aren't able to work, there's people that aren't able to leave the house because they're having multiple seizures a day so it [reading posts in support groups] just sort of, kind of, keeps you grounded and makes you think: 'Actually, hang on a minute, we're doing alright here.'" (Millie).

"Having advice from people who have already been there and are that little bit further on than you are in the journey really helps." (Ian).

Connections with other carers were identified as valuable in counterbalancing challenging reactions to NEAD encountered in other interactions.

Theme three: The importance of having an explanatory framework for seizures

Post-diagnostic information and support, like diagnosis, was largely described as difficult to access. Those who did access such support and came to develop a working understanding of their loved ones' seizures, identified this, rather than diagnosis itself, as the critical factor which lead to changes in their own sense of coping and wellbeing.

3.1 'There were no answers, no real answers'

Receiving an official diagnosis of NEAD was not experienced as being the 'answer' carers were seeking. Information beyond communication of the diagnosis of NEAD was not, however, reported to be routinely provided by the medical professionals that carers encountered. The majority of carers reported

initially relying largely on independent research to try and gain further understanding of NEAD, with variable success. Coming to understand more about NEAD was often reported to take several years and signposting to quality resources was very much appreciated. Furthermore, carers often reported obtaining such information through personal connections, suggesting an element of luck and unequal distribution of resources:

"Once we got the diagnosis of NEAD, it wasn't even the hospital that sat down with me it was actually a friend of mine whose friend is a doctor. And I said: 'What happens if she's crossing the road and she collapses and she…. and she gets run over?' and she said: 'It won't happen like that', she said: 'It doesn't happen like that.'" (Rachel).

Common topics that carers wished had been discussed alongside the diagnosis of NEAD were its anticipated course, management ideas and strategies to identify triggers and warning signs.

Two participants did describe positive experiences of the communication of the diagnosis and signposting to further support at this stage. Where this was provided, it was reported to help form realistic expectations for the future:

"I think it [information about expected prognosis] actually solidified that: 'Okay, I'm her carer now' and it's not: 'Okay, well in six months' time she's going to be better so we can sort of go back to the way we were'…I think that definitely made a difference, made me feel as if we could move forwards." (Ian).

The provision of information that helped deepen carer understanding of their family member's seizures was valued over the communication of the diagnosis itself yet was experienced as rare and difficult to access.

3.2: 'It's much easier to deal with if you have a story you can tell'

All carers sought to understand their family members seizures. After initially suspecting a biomedical cause for their family members' seizures, carers reported considering other psychological, environmental and social factors. For

some, psychological explanations made sense and seizures came to be seen as part of wider mental health conditions. In two instances, for example, seizures came to be understood as a feature of PTSD in response to specific, traumatic events:

"So, it's his brain's way of dealing with things that really, he doesn't want to face full-on and have to go through again so his brain just switches off in those occasions where there's been noises or around anniversaries [triggers]." (Gemma).

Remaining carers differed in terms of whether they felt they needed an explanation for why the seizures first started and whether they accepted links with past trauma reportedly suggested by services. Many instead described more present-focused explanations of seizures. For example, carers described having identified a mix of psychological and non-psychological triggers for seizures including stress, temperature changes, flashing lights and tiredness:

"The way I explain it is that it's a coping mechanism and her brain has found that if she does this, it… it's because she's really stressed and it takes away from the stress, you know, that's what the brain has discovered." (Annika).

Two carers did not yet feel they understood their family member's seizures. For Rachel, for example, psychological explanations were experienced as completely at odds with her daughter's seizures, yet seemed to be relentlessly endorsed by services:

"*They [healthcare staff] were on about: ''It's stress, it's stress, it's stress' and she [daughter] was like: 'But I'm not stressed!'" (Rachel).*

Carers who felt they had developed an explanatory framework for their family members' seizures described multiple benefits of this, including feeling more able to identify triggers and warning signs, being able to explain seizures to others, and developing hope that seizures could improve with therapy:

"I think it does help her to believe that that [traumatic event] was the cause and that, therefore, if she has appropriate therapy and can work through that, they will get better. And from what I understand now… her belief and our belief that

they will get better is helping them to get better, if you see what I mean." (Carol).

Explanatory frameworks were highly idiosyncratic and differed across carers in terms of the perceived importance of historic factors and the relative perceived contribution of different biopsychosocial factors. Those who did not yet feel they had developed an explanatory framework desired this.

3.3 'A whole different way of approaching the seizures'

It was common for carers to describe a change in how they supported their family members over time. Familiarity with their loved ones' seizures was highlighted as a contributing factor to this for all; familiarity allowing carers to tolerate the distress of witnessing their family member in seizure and refrain from routinely seeking urgent medical attention:

"I tend not to panic now because I know how they progress, how they progress and how she'll get over it." (Jeanette).

Additional changes in caring style were, however, described by the six carers who felt they had come to develop an understanding of their family members' seizures. Multiple carers reported, for example, that becoming aware of triggers had allowed them to feel better able to manage the aforementioned difficulty (subtheme 1.2) in balancing protection and the promotion of independence:

"It's not in her interests to be tied to me. She needs to be out there and meet other people, and learn to stand on her own two feet and I wouldn't be a very good mother if I didn't try and make her do that, so… yea, with a safety net." (Carol).

Other changes in approach following understanding included a shift in focus from trying to find a way to stop the seizures, to finding a way to incorporate them into family life:

“We laugh sometimes, we say, we tend to treat them like a petulant child at times or a toddler. You keep them fed, plenty of sleep, you know, water, not too hot, not too cold and they behave themselves better.” (Ian).

These changes involved active effort from carers to override their instinctual response of how to care for their family member. Several carers mentioned techniques they used to help themselves in this regard, which, in psychological terms, can be described as distraction, challenging worrying thoughts, mindfulness and trying to avoid overthinking things that were out of their control.

Individualised understanding of seizures was identified as something which lead to changes in caring style and carer wellbeing. These changes went beyond those which resulted from experience and familiarity.

Discussion

This study explored the lived experiences of individuals caring for an adult family member diagnosed with Non-Epileptic Attack Disorder (NEAD). Three interconnected themes captured the essence of carer accounts: the personal impact of caring, navigating others' reactions, and the benefit of having an explanatory framework for seizures. Across accounts, experiencing relationships with professionals as collaborative and respectful, and the provision of information which developed understanding appeared to facilitate changes in caring approach and ultimately, carer wellbeing.

The first theme related to the personal impact of caring. All carers described a point in time where their role supporting their family member with NEAD overshadowed other previously valued aspects of their identity. This is in keeping with the previously identified theme of role engulfment and loss of self in caregiving (Eifert et al., 2015), where the caring role becomes more dominant than any other. In line with research with other carer groups (e.g. COPD: Simpson et al., 2010; cancer: Ugdale et al., 2012), those carers who maintained aspects of their pre-caregiving identity and found ways to continue to incorporate previously enjoyed and meaningful activities into their life reported feeling less distressed and overwhelmed in the caring role.

Differences in motivation for caring are a potential explanation for why only the two carers whose partners' seizures predated their relationship spontaneously reported a sense of accomplishment and purpose through caring. Self-determination theory (Deci & Ryan, 1985) proposes that behaviour is motivated either by autonomous or controlled reasons: autonomously motivated help phenomenologically being experienced as a "want" and control motivated help being experienced as a "should" (Kindt et al., 2019). Autonomously motivated caring, as opposed to control motivated caring, has been associated with carers finding more benefit in the caring role (Kim et al., 2008) and care recipients feeling that their psychological needs are better met (Kindt et al., 2019). Those entering into caring relationships through choice could arguably be more likely to be acting autonomously rather than out of a sense of duty and this may explain the sense of personal reward reported by the two carers in this position.

The theme of navigating the reactions of others captured how carers commonly encountered a lack of awareness of NEAD and doubt of its legitimacy, both within services and wider society. This finding echoes the experiences of both those diagnosed with NEAD (Rawlings et al., 2017) and parents caring for children with NEAD (McWilliams et al., 2016). Individuals diagnosed with NEAD have reported that such perceived disregard can discourage them from engaging with services (Dickinson et al., 2011). The carers in this study instead responded with assertiveness, acting as an advocate for their loved one and "pushing" for support where this was not provided. This may account for the recent finding that having a carer predicts attendance at initial psychiatry appointment (Stone et al., 2020).

The desire to be believed, respected and involved in their family members' care was strong across carer accounts and instances of feeling treated this way, although rare, were experienced to relieve burden, and were meaningful and memorable. This is in keeping with reports that empathic relationships with care providers mediated the negative impact of uncertainty and appointment delays in individuals with medically unexplained symptoms (Kornelsen et al., 2016); and suggests that for carers also, relationship-based care is of central importance. Indeed, one-off contacts with supportive health care professionals were valued. This is concordant with findings that carers rate personal contact as the most beneficial source of information (Kendall et al., 2004), valuing accompanying written materials for consolidation but not in isolation (Mastwyk et al., 2014).

The third theme related to the importance of having an explanatory framework for seizures. Six participants described having developed a working understanding of their family members' seizures, and the two remaining carers desired this (subtheme 3.2). Explanatory frameworks were highly idiosyncratic and were described as developing gradually through increased understanding, potentially representing shifting illness perceptions (Leventhal et al., 1997) and the gradual construction of a biopsychosocial causal framework (Brown & Reuber, 2016). Many carers described having to overcome perceived inadequacies in information provision and support to develop such understanding. Once developed, however, explanatory frameworks facilitated

changes in caring approach beyond those resulting from familiarity with seizures. Carers who felt they had developed an understanding of their family members' seizures reported, for example, having learnt to override their initial instinct to protect and shelter their family member through constant supervision, and having come to accept seizures, worry less and incorporate them into family life. Coping literature suggests that effective coping requires a combination of problem-focused strategies, such as solution generation, and emotion-focused strategies, such as acceptance (Lazarus & Folkman, 1984). Research with dementia carers has, likewise, identified that acceptance and active problem solving are associated with better carer mental health outcomes than avoidance and denial (Gilhooly et al., 2016). It may be that the development of an explanatory framework facilitated carer acceptance and proactive action in response to caregiving demands.

Limitations

Participants were recruited through social media, and the sample therefore consisted of carers who had sought support online. Participants spoke of the benefits of peer support and their experiences may therefore be different to those who have not accessed such support. The nature of recruitment also meant that verification of the diagnosis of NEAD was not possible. Additionally, participant ethnicity and race were not recorded, and this restricts accurate description of the sample and consideration of the impact of these factors.

As has previously been reported as common in this population (Bodde et al., 2009, McWilliams et al., 2019), the sample was diverse in that some carers reported that those they supported had conditions such as functional movement disorder or autism in addition to NEAD. The researcher took care to communicate that the research was focused specifically on carers' experiences of supporting their family member with their seizures and sought clarity during interviews if it was unclear whether carers were talking about an aspect of their caring role that related to a different condition. It is, however, recognised that separating such experiences may not always be possible.

The researcher was transparent with subjects about her role as a Clinical Psychologist in training within the NHS. It is possible that her job role and affiliation with the health service may have led participants to censor strong opinions about services or psychological models of NEAD, potentially diluting some of the experiences shared.

Reflections

Consultation of the reflective research journal helped the researcher consider whether her own opinions, emotional responses and biases may be influencing her analysis. For example, the researcher noted she felt compelled to try and help Rachel in some way at points throughout her interview (Appendix N). The researcher was aware of her desire to offer participants something in return for their participation through the results of this study. There was a risk of this influencing analysis through the researcher overemphasising challenges to make a compelling case for increased support. To counteract this, the researcher made sure that all analysis was grounded in the words and context of participant accounts.

Future Research

Carers in the current study who felt they had come to develop an understanding of their family members' NEAD reported this led to positive changes such as reduced worry, increased confidence in caring and acceptance. Future research is required to establish whether this experience is shared by carers for adult family members with NEAD more generally. Future research could also explore the effect of deliberate interventions to help carers develop robust biopsychosocial conceptualisations of NEAD. Whilst some psychoeducation interventions have been attended by both carers and individuals with NEAD (e.g. Metin et al., 2013; Chen et al., 2014), to the best of the authors knowledge, carer outcomes, and their interaction with client outcomes, have yet to be investigated.

The results of the current study discourage family caregivers for those diagnosed with NEAD being treated as a homogenous group. Although there was overlap, differences emerged between parent and spousal caregivers as well as those whose relationship pre-dated their family members' seizures and those whose did not. Future research focusing on specific carer subgroups would allow more specific conclusions to be drawn. Participant ethnicity and race should be recorded and their impact on experience considered in future research.

Clinical Implications

The experiences of carers in the current study suggest potential benefits of individualised formulation work following diagnosis, and the inclusion of carers in this process. This could confer benefits for those experiencing seizures, as well as carers. The inclusion of carers in assessment appointments would, for example, allow clinicians to better consider systemic factors, such as family illness beliefs, which may be a maintaining factor for seizures. Carers may also be able to offer insight into seizure triggers and inform the selection of appropriate psychological therapy. If carers identify that seizures are triggered in phobic situations, for example, cognitive behavioural approaches such as graded exposure therapy may be indicated (McWilliams et al., 2016).

Carers in this study differed in whether they were interested in developing a longitudinal formulation of their family members' seizures or were satisfied with a present-focused understanding of triggers and warning signs. The role of psychological variables in NEAD were also typically only considered after the exclusion of organic causes. These factors suggest that the timing and nature of any formulation work offered should be tailored to family need and preference.

All carers described actively seeking post diagnostic support and information and this was highly valued where received. The report of carers in this study suggests that information about the expected course of NEAD, management strategies and trigger and warning sign identification would be highly valued.

In line with multiple policy directives (DoH, 2018; NICE, 2020), healthcare professionals should avoid positioning carers only as agents for change in the person they care for and ensure carers' own needs are considered. The experiences of carers in the current study suggest that assertiveness training to help manage the challenging reactions of others and psychological strategies for managing worry, increasing self-care and encouraging engagement with personally valued activities may represent appropriate interventions for carers. As observed in other carer groups (Greenwood et al., 2013), peer support was highly valued by carers in the current study and group delivery may therefore represent an appropriate method of delivery for carer psychological support.

Some of the challenges carers reported facing were systemic and have been well documented in previous research (e.g. Duncan et al., 2010; Rawlings & Reuber, 2018). The development of a clear pathway for individuals with NEAD, increasing understanding of NEAD through staff training and improving partnership working between mental and physical health services would help ensure more equitable and direct access to support and reduce this aspect of caregiver burden.

Conclusion

This study extends our understanding of the experiences of those caring for an adult family member diagnosed with NEAD and emphasises the value of improving support and education for carers. Caring was reported to have a restrictive impact on multiple areas of carers' lives and was made more challenging by the perceived widespread lack of awareness of, and sometimes even belief in, NEAD. Although reportedly difficult to access, relationships with professionals that were experienced as respectful and collaborative, and the provision of information which developed carers biopsychosocial understanding of NEAD, facilitated changes in caring approach and, ultimately, carer wellbeing. Purposeful inclusion of carers in NEAD care pathways may offer opportunity for these effects to be maximised. Such changes may also confer benefits to individuals with NEAD themselves.

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Appendices

Appendix A: Manuscript submission guidelines for Qualitative Health Research

Complete Manuscript Submission guidelines can be found at: https://journals.sagepub.com/pb-assets/cmscontent/QHR/QHR%20Manuscript%20Submission%20Guidelines%20-%205.1.2019.pdf

4.1 Article Format (see previously published articles in QHR for style):

- Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.
- Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.
- Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

- Please do not refer to your manuscript as a "paper;" you are submitting an "article."
- The word "data" is plural.

4.2 Word processing formats

- Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1-inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

4.3 Artwork, figures and other graphics

- Figures: Should clarify text.
- Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.

- Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e. INSERT TABLE 1 HERE).
- Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor.
  - TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
  - Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
  - Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

Appendix B: Study advert

Do you support a family member or partner with Non Epileptic Attack Disorder (NEAD)?

STAFFORDSHIRE UNIVERSITY

We are doing some research to try and better understand what it is like to care for somebody diagnosed with NEAD.

We would like to talk to you if:

- You care for a family member/ partner who was diagnosed with NEAD by a medical professional over one year ago
- You are aged 18 + and care for somebody aged 18+
- You live with the person you care for or provide care at least 5 days a week
- You would describe yourself as your family member's main carer
- The person you care for is not also diagnosed with Epilepsy
- You speak English
- You live in the UK

If you volunteer to take part you will be asked to :

- Answer some yes/ no questions about yourself and the person you care for to check you meet the study criteria (shown on left).
- Be interviewed either in person at Staffordshire University or by Skype or phone if you prefer.

If you would like to take part :

Please contact Sarah Brookes on the email address below

Who is sponsoring the study?

The study is being done as part of the researcher's professional doctorate in Clinical Psychology training at Staffordshire University.

Contacts:

Principal Researcher: Sarah Brookes (sarah.brookes@student.staffs.ac.uk)
Research supervisor: Dr Helen Scott (H.scott@staffs.ac.uk)

Appendix C: Participant information sheet

The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD)

Introduction:

We would like to invite you to take part in a research study. The study is being carried out by Sarah Brookes as part of her doctoral training in Clinical Psychology at Staffordshire University.

Please read this information sheet carefully to find out more about why the research is being done and what taking part would involve. If there is anything that is not clear or if you would like more information, please get in touch using the contact details below. Take your time deciding whether you would like to take part and feel free to discuss your decision with others if you would like to.

Why is the research being carried out?

We are interested in speaking to people who care for an adult family member or partner who has a diagnosis of Non-Epileptic Attack Disorder (NEAD). Only a small amount of previous research has involved carers and we think it is important to understand more about their experiences.

Can I take part?

For the purposes of the study, we need to talk to a group of carers who have important things in common so that we are able to compare their experiences.

You can take part if:

- You care for a family member/ partner who has received a diagnosis of NEAD from a medical professional.
- Your family member/ partner was diagnosed with NEAD over one year ago
- Both you and the person you care for are aged over 18
- You live with the person you care for or provide care at least 5 days a week
- You are your family member/ partner's main carer
- The person you care for does not also have epilepsy
- You live in the UK
- You speak English

What would taking part involve?

If you decide to take part in the study, you will first be sent an information sheet with more information about the study and asked to answer some yes or no questions about yourself and the person you care for. If you meet the criteria to take part (listed above), you will be sent a consent form to complete and return. You will then be contacted to arrange an interview with myself, Sarah Brookes, at a time that is convenient for you. The interview can either be done in person at Staffordshire University or by Skype or telephone depending what you would prefer. If you chose to do the interview over the phone or Skype you will need to be able to do this from a private space where you will not be overheard by others or the person you care for. You will also be asked to tell the researcher the address from which you are taking part and provide an emergency contact number in case of emergency. The interview will last between 60-90 minutes and will be audio recorded. During the interview you will be asked to share your experiences of supporting your family member/ partner. Examples of things you might be asked about include: what care you provide, the impact of providing this care, what helps you care for your family member/ partner and how you make sense of NEAD.

Can I change my mind about taking part?

You are welcome to change your mind about taking part in the study without having to give a reason. If you take part in an interview and later decide you do not want to be part of the study, please contact us within two weeks of the date of your interview. Any information you provided will be destroyed at this point. It will no longer be possible to withdraw from the study after two weeks of the date of your interview. This is because we will have anonymised the information from your interview and started analysing it alongside the information of others who took part.

Are there any benefits of taking part?

We cannot guarantee any immediate benefits from taking part in the study. Through sharing your experiences, you will be increasing understanding about what it is like to care for somebody with NEAD. It is hoped this will help inform services and shape support available both for people who have NEAD and those who support them.

Are there any disadvantages of taking part?

There is a possibility that talking about your experiences of supporting somebody who has NEAD may cause you some emotional distress or anxiety. You do not have to answer any questions you do not want to and can have a break or stop the interview at any time, without having to give an explanation.

What will happen with my information?

The recording of your interview will be typed up by the principal researcher. Your name and all other names mentioned in your interview will be changed at this point so that you are not identifiable. With your consent, direct quotes from your interview will be used in the write-up of the study. Whilst you may be able to recognise your own quotes, care will be taken to ensure that they are not identifiable to others. However, you need to be aware that people who know you well might be able to recognise your information in the write up of the study if you tell them you took part.

All information you provide will be stored securely and confidentially. Following university regulations, a typed-up version of your interview and your answers to questions about yourself and the person you support will be stored securely in electronic format for ten years, before being destroyed. If you do not ask for a summary of the research findings, personal details such as your name and contact details will be destroyed two weeks after the date of your interview. If you do request a summary of the study findings, your personal details will be destroyed after this has been sent to you at the end of the research project. The audio recording of your interview will be destroyed at the end of the research project.

The information you provide will be used only for the purpose of this research project. The only exception to this would be in the event that you share information suggesting that either you or others are at serious risk of harm. In the unlikely event of this happening, we may need to share information with an organisation such as the emergency services to ensure your safety. This would be discussed with you and the research supervisor first of all.

University data protection statement:

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the Staffordshire University Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk

What will happen with the results of the study?

It is expected the research will be completed by September 2020. The study will be written up and submitted to Staffordshire University as part of the primary researcher's professional training. It will also be submitted for publication in an academic journal and may be presented at research conferences. You can request a summary of the results of the study either during your interview or by contacting the primary researcher on the email address below at any point.

Sources of support:

The table below contains details of organisations that are able to provide information about NEAD and/ or offer support in relation to your caring role.

FND (Functional Neurological Disorder) Action – Website has information about NEAD. Facebook support group for carers also available. – W: https://www.fndaction.org.uk/carers/ – Facebook:https://www.facebook.com/groups/624529534403038/	**Samaritans UK** – A 24-hour helpline offering emotional support for anybody in emotional distress. – E: jo@samaritans.org – T: 116 123 (Freephone) – W: www.samaritans.org
Carers UK – Provide information, support and advice to carers. – E: advice@carersuk.org – T: 0808 808 7777 – W: www.carersuk.org	**Your GP** – Will be aware of local mental health services and options for emotional support.

Contact details:

Please feel free to contact me with any further questions or concerns you have about the research study. My research supervisor is also available to be contacted if required.

Primary Researcher: Sarah Brookes (sarah.brookes@student.staffs.ac.uk)
Research supervisor: Dr Helen Scott (h.scott@staffs.ac.uk)

Department of Clinical Psychology,
Science Building, Staffordshire University,
32 Leek Road, Stoke-on-Trent,
ST4 2AR

Appendix D: Screening Questions

Please answer the yes/ no questions below. The questions are about you and the person you care for.

As described in the study advert and information sheet, we are looking to interview carers who meet certain criteria. This will mean that the group of carers we interview have important things in common so that we can compare their experiences. Your answers to these questions will help us know whether or not you are able to take part in the study.

1. Do you care for a partner or family member with NEAD?
   (Yes/No)

2. Are both you and the person you care for aged over 18?
   (Yes/ No)

3. Was the person you support diagnosed with NEAD by a health professional?
   (Yes/ No)

4. Was the person you support diagnosed with NEAD over one year ago?
   (Yes/ No)

5. Do you live with the person you care for or care for them at least 5 days a week?
   (Yes/ No)

6. Would you describe yourself as the person your family member/ partner's main carer?
   (Yes/ No/ Free text response box)

7. Does the person you care for only experience non epileptic attacks? (i.e. they are not also diagnosed with epilepsy)
   (Yes/ No/ Free Text Response Box)

8. Do you live in in the United Kingdom (UK)?
   (Yes/ No)

9. Do you speak English and feel able to take part in a 60-90-minute interview in English?
   (Yes/ No)

Please contact the principal researcher if you have any questions or concerns about these screening questions.

Appendix E: Participant consent form

Project Title: The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD).

Primary Researcher: Sarah Brookes, Trainee Clinical Psychologist

Please initial to confirm that you agree with the statements below:

		Please Initial
1.	I have read the information sheet about the above study. I have had the opportunity to consider this information and ask questions. I am happy with answers I was given to any question asked.	
2.	I understand that I don't have to take part in the study and that I can stop the interview at any time without having to give a reason. I understand that I can withdraw my information for up to two weeks following the date of my interview without having to give a reason.	
3.	I consent to my interview being audio-recorded for the purposes of this research project.	
4.	I consent to direct quotes from my interview being used in the write-up of the study. I understand that all names will be changed to protect my anonymity. I am aware there is a chance people who know me well might recognise my information if I tell them I took part in the study.	
5.	I agree that the information I provide within the study can be used anonymously for the purposes of research and publication.	
6.	If I take part in an interview over the telephone or skype, I agree to tell the primary researcher the address I will be taking part from and provide the name and telephone number of an emergency contact person.	
7.	**I agree to take part in the above-named study**	

Participant Name:		Participant Signature:		Date:	
Researcher Name:		Researcher Signature:		Date:	

Appendix F: Demographic information questions and interview topic guide

Introduction:

- Introduce self and study
- Discuss anonymity and privacy. Check for participant queries/ continued consent.
- For telephone/ Skype interviews: remind participant to make sure they are in a private room and cannot be overheard. Ask for location and emergency contact name and telephone number.

Demographic information questions:

"First of all I would like to ask you some short questions about you and the person you care for so as we can describe the group of people who take part in the interviews when we write up the study."

1. How old are you?
2. How old is the person you care for?
3. When did the person you care for have their first seizure?
4. When was the person you care for diagnosed with NEAD?
5. How many seizures would you estimate the person you care for has in an average week?
6. When was their last seizure?
7. How many hours per week do you spend caring for your family member/partner?
8. How long have you cared for your family member?
9. Do you have any health problems?
10. Does the person you support have any other health problems?

Interview Topic Guide:

"Next I would like to hear about your experiences of caring for your family member/ partner. I have some questions we can use to guide our conversation but you are the expert here and we may well end up talking about something important you raise even if it is not on this list of questions. It is likely that you will do a lot more of the talking than me and I might ask you to tell me even more about some of the things you mention if that is okay, so as we can get some really detailed information about what it's like for you being a carer"

1. What day to day support do you offer your family member/ partner with NEAD?

2. Has the way in which you support your family member/partner changed over time since the symptoms started to now?
   Prompts: before diagnosis, shortly after diagnosis and onwards.

3. What has it been like for you providing this support?
   Prompts- has this impacted your life/ health/ psychological wellbeing?

4. What kind of challenges have you encountered whilst caring for your partner/ family member?

5. Has caring for your family member/ partner affected your relationship?

6. Is there anything that has helped you support your family member/partner?

7. Is there any advice you would give to others in your position?

8. Is there any advice you would give to services in regards to how best to support people with NEAD and their families/ partners?

9. How do you make sense of your family member/ partners attacks?

10. "Is there anything in relation to your caring role that we haven't spoken about yet that you think it is important we talk about?"

End
Thank participant
Check for further queries
Provide with debrief sheet

Appendix G: Participant debrief sheet

Project Title:
The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD)

Primary Researcher:
Sarah Brookes, Trainee Clinical Psychologist

Thank you for taking part in this research project

We were interested in learning more about the experiences of those who support and care for a family member or partner diagnosed with Non-Epileptic Attack Disorder (NEAD).

Very little research has focused on asking those who care for people with NEAD about their experiences of providing this support. Previous research undertaken with carers for people with other health conditions suggests that whilst caring can sometimes be rewarding it can also be both practically and emotionally challenging. Through asking you about your experiences we hope to help develop an evidence base that will inform future policy and practice and enable both individuals with NEAD and those who care for them to be offered appropriate support.

If you have indicated that you would like to receive a summary of the study results, you will receive this by September 2020 using the contact details you have provided.

Sources of further support:

Talking about difficult experiences can sometimes make us feel upset or distressed. This is a natural human response. If such feelings do not pass or you think you would benefit from further support around some of the topics covered in our discussion today the below agencies may be able to offer information/ support.

FND (Functional Neurological Disorder) Action – Website has information about NEAD. Facebook support group for carers also available. – W: https://www.fndaction.org.uk/carers/ – Facebook:https://www.facebook.com/groups/624529534403038/	**Samaritans UK** – A 24-hour helpline offering emotional support for anybody in emotional distress. – E: jo@samaritans.org – T: 116 123 (Freephone) – W: www.samaritans.org
Carers UK – Provide information, support and advice to carers. – E: advice@carersuk.org – T: 0808 808 7777 – W: www.carersuk.org	**Your GP** – Will be aware of local mental health services and options for emotional support.

Thank you again for your contribution to this research. Please feel free to contact me or my research supervisor with any questions or concerns about your participation.

Yours sincerely,

Sarah Brookes

Trainee Clinical Psychologist
Sarah.brookes@student.staffs.ac.uk

Research supervised by:
Dr Helen Scott, Research Director & Clinical Psychologist
H.scott@staffs.ac.uk

Department of Clinical Psychology,
Science Building, Staffordshire University,
32 Leek Road,
Stoke-on-Trent,
ST4 2AR

Appendix H: Ethical Approval from Staffordshire University

Life Sciences and Education

ETHICAL APPROVAL FEEDBACK

Researcher name:	Sarah Brookes
Title of Study:	The experiences of family carers supporting adults diagnosed with Non Epileptic Attack Disorder (NEAD)
Award Pathway:	Doctorate
Status of approval:	Approved

Your project ***proposal has been approved*** by the Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

The Ethics Committee wish you well with your research.

Signed: Prof. Roozbeh Naemi **Date: 26.09.2019**

Ethics Coordinator
School of Life Sciences and Education

Appendix I: Kasket (2009) risk protocol for remote interviews

Protocol for Responding to Participant Distress,

Adapted Version for Telephone/Skype

Notes: This protocol for responding to research participant distress over the telephone has been adapted from the one devised by Cocking (2008). Adaptations have been made to reflect the fact that interviews may not always take place face to face.

Steps taken prior to commencement of interview questions:

1) Consider giving questions to the participant in advance so that the participant can acclimate to the idea of these questions being asked.
2) Seek the first and last name of participant and the town/city of current residence, in order to facilitate contacting emergency services if necessary.
3) Obtain emergency contact number from the participant. The participant should be informed in the informed consent that if the researcher has significant concerns about the participant's safety, and/or if the telephone conversation is terminated in the context of severe distress, the researcher may need to use this emergency contact.
4) Appropriate helpline(s) in each participant's area should be identified by the researcher in order to be able to offer participants immediate further sources of support if distress arises in an interview.

Mild distress:

Signs to listen out for:

1) Sounds that indicate participant may be weeping, e.g., sniffling, hesitation.
2) Voice becomes choked with emotion, or the participant has difficulty speaking or has a tremulous voice
3) Verbal signals such as “This is really hard for me to talk about”, or “I didn’t realise it would affect me so much to talk about it”.

Actions to take:

1) Ask participant if they are okay to continue
2) Offer them time to pause and compose themselves
3) Remind them they can stop at any time they wish if they become too distressed

Severe distress:

Signs to listen out for:

1) Uncontrolled crying/ wailing/heavy sobs, inability to talk coherently
2) Expressions of strong feelings of personal guilt or responsibility for a negative event or harm to others (if applicable to topic)
3) Signs of high anxiety or panic attack, as heard by researcher and/or as reported by participant, e.g., hyperventilation, shaking

Actions to take:

1) The researcher should intervene to terminate the interview
2) The debrief will begin immediately
3) Relaxation techniques will be suggested to regulate breathing and reduce agitation
4) The researcher should acknowledge the participant’s distress, and reassure him/her that (for example, according to topic) the experience that they’re describing can be quite traumatic or difficult and can sometimes result in traumatic stress reactions.
5) If any unresolved issues arise during the interview, accept and validate the participant’s distress, but suggest that s/he discuss with mental health professionals and remind the participant that this is not designed as a therapeutic intervention.

6) Offer details of counselling/therapeutic/helpline services available to participants (see point 4 under “steps taken prior to commencement of interview questions”, above)

Extreme distress:

Signs to listen out for:

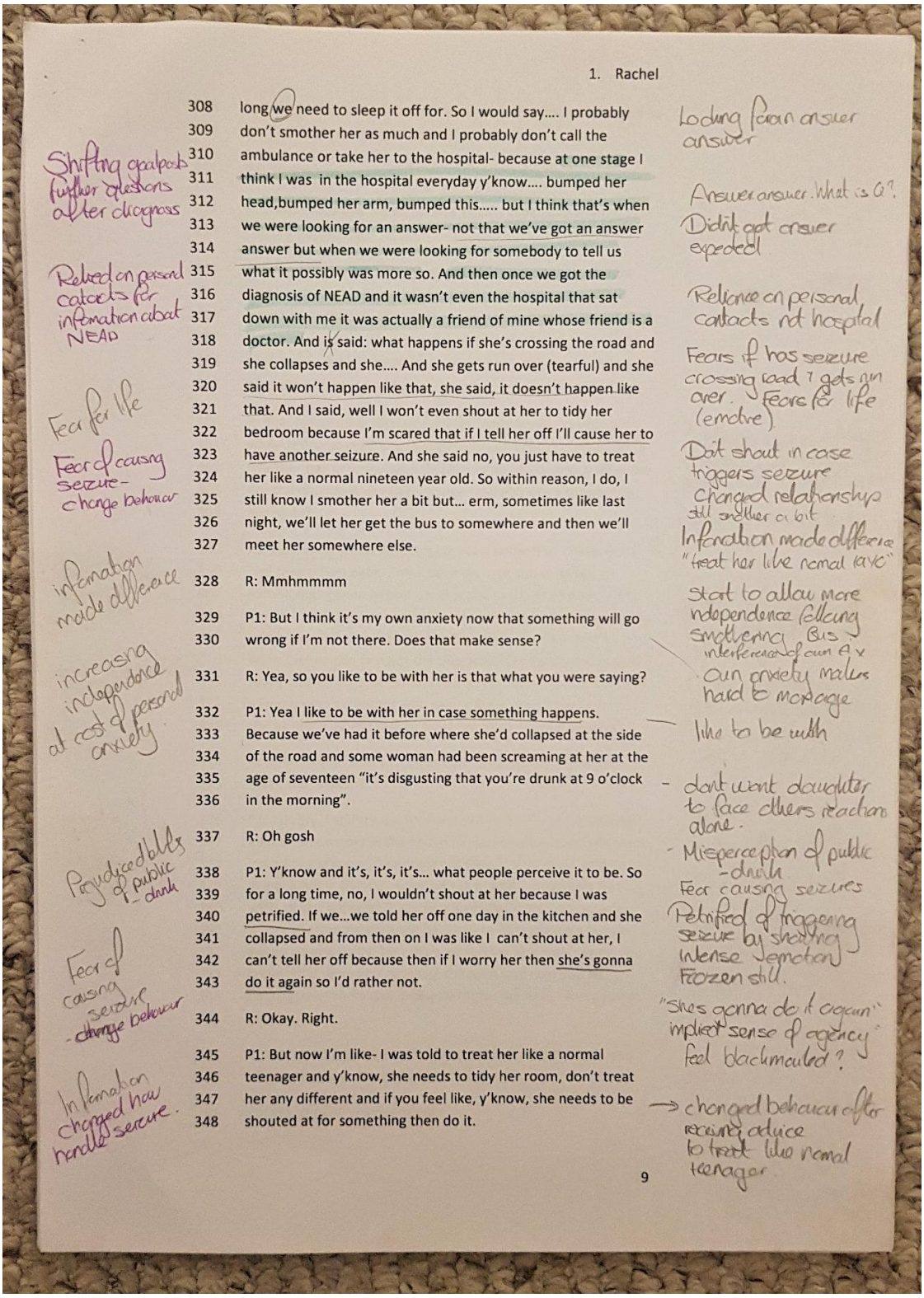
1) Severe agitation, lack of coherence, especially coupled with sudden termination of telephone connection.
2) Verbal indications of suicidality, especially coupled with sudden termination of telephone connection.

Action to take:

1) If termination of telephone connection has occurred, attempt to re-contact. If this is unsuccessful, and termination occurred *in the context of a level of agitation or emotionality that caused the researcher concern for the participant's or others' safety,* inform emergency contact and/or local emergency services.
2) If the researcher has concerns for the participant's or others' safety and the participant is still on the line, s/he will inform them that s/he has a duty to inform the emergency contact provided and/or local emergency services.

If the researcher believes that either the participant or someone else is in immediate danger and the participant is still on the line, then the researcher will suggest that the participant presents him- or herself to the nearest Accident & Emergency department, and it may also be necessary for the researcher to contact the emergency contact.

Appendix J: Example of initial noting and emergent theme generation on transcript



1. Rachel

308 long we need to sleep it off for. So I would say.... I probably
309 don't smother her as much and I probably don't call the
310 ambulance or take her to the hospital- because at one stage I
311 think I was in the hospital everyday y'know.... bumped her
312 head,bumped her arm, bumped this..... but I think that's when
313 we were looking for an answer- not that we've got an answer
314 answer but when we were looking for somebody to tell us
315 what it possibly was more so. And then once we got the
316 diagnosis of NEAD and it wasn't even the hospital that sat
317 down with me it was actually a friend of mine whose friend is a
318 doctor. And is said: what happens if she's crossing the road and
319 she collapses and she.... And she gets run over (tearful) and she
320 said it won't happen like that, she said, it doesn't happen like
321 that. And I said, well I won't even shout at her to tidy her
322 bedroom because I'm scared that if I tell her off I'll cause her to
323 have another seizure. And she said no, you just have to treat
324 her like a normal nineteen year old. So within reason, I do, I
325 still know I smother her a bit but... erm, sometimes like last
326 night, we'll let her get the bus to somewhere and then we'll
327 meet her somewhere else.

328 R: Mmhmmmm

329 P1: But I think it's my own anxiety now that something will go
330 wrong if I'm not there. Does that make sense?

331 R: Yea, so you like to be with her is that what you were saying?

332 P1: Yea I like to be with her in case something happens.
333 Because we've had it before where she'd collapsed at the side
334 of the road and some woman had been screaming at her at the
335 age of seventeen "it's disgusting that you're drunk at 9 o'clock
336 in the morning".

337 R: Oh gosh

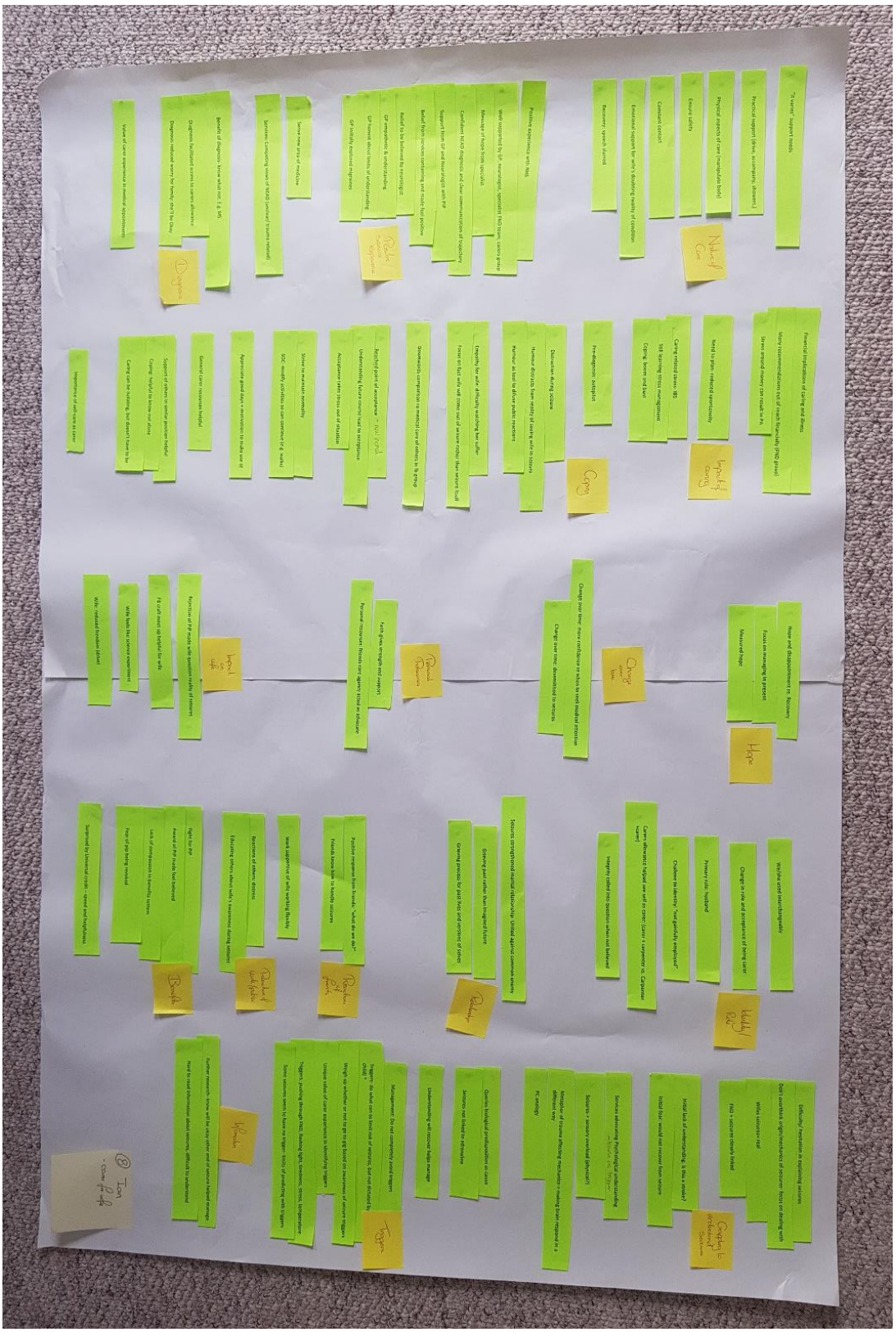
338 P1: Y'know and it's, it's, it's... what people perceive it to be. So
339 for a long time, no, I wouldn't shout at her because I was
340 petrified. If we...we told her off one day in the kitchen and she
341 collapsed and from then on I was like I can't shout at her, I
342 can't tell her off because then if I worry her then she's gonna
343 do it again so I'd rather not.

344 R: Okay. Right.

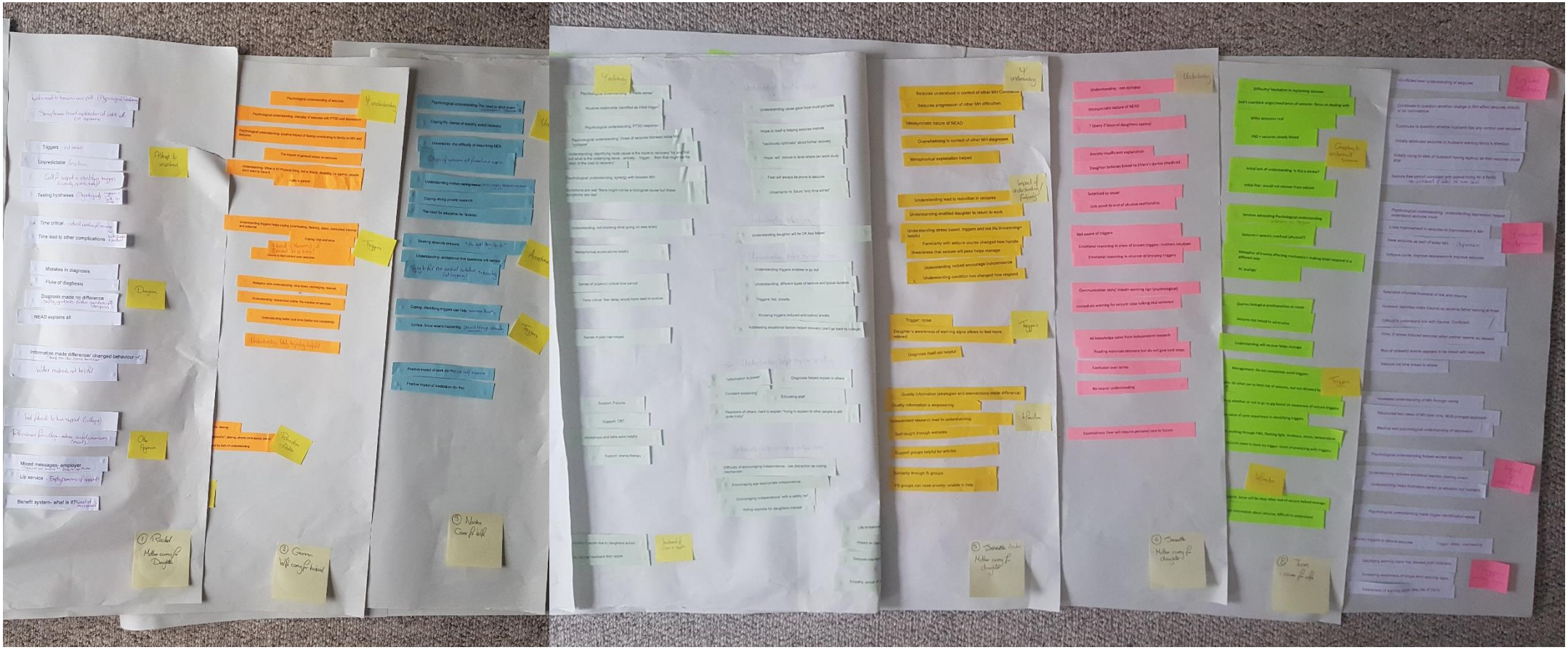
345 P1: But now I'm like- I was told to treat her like a normal
346 teenager and y'know, she needs to tidy her room, don't treat
347 her any different and if you feel like, y'know, she needs to be
348 shouted at for something then do it.

9

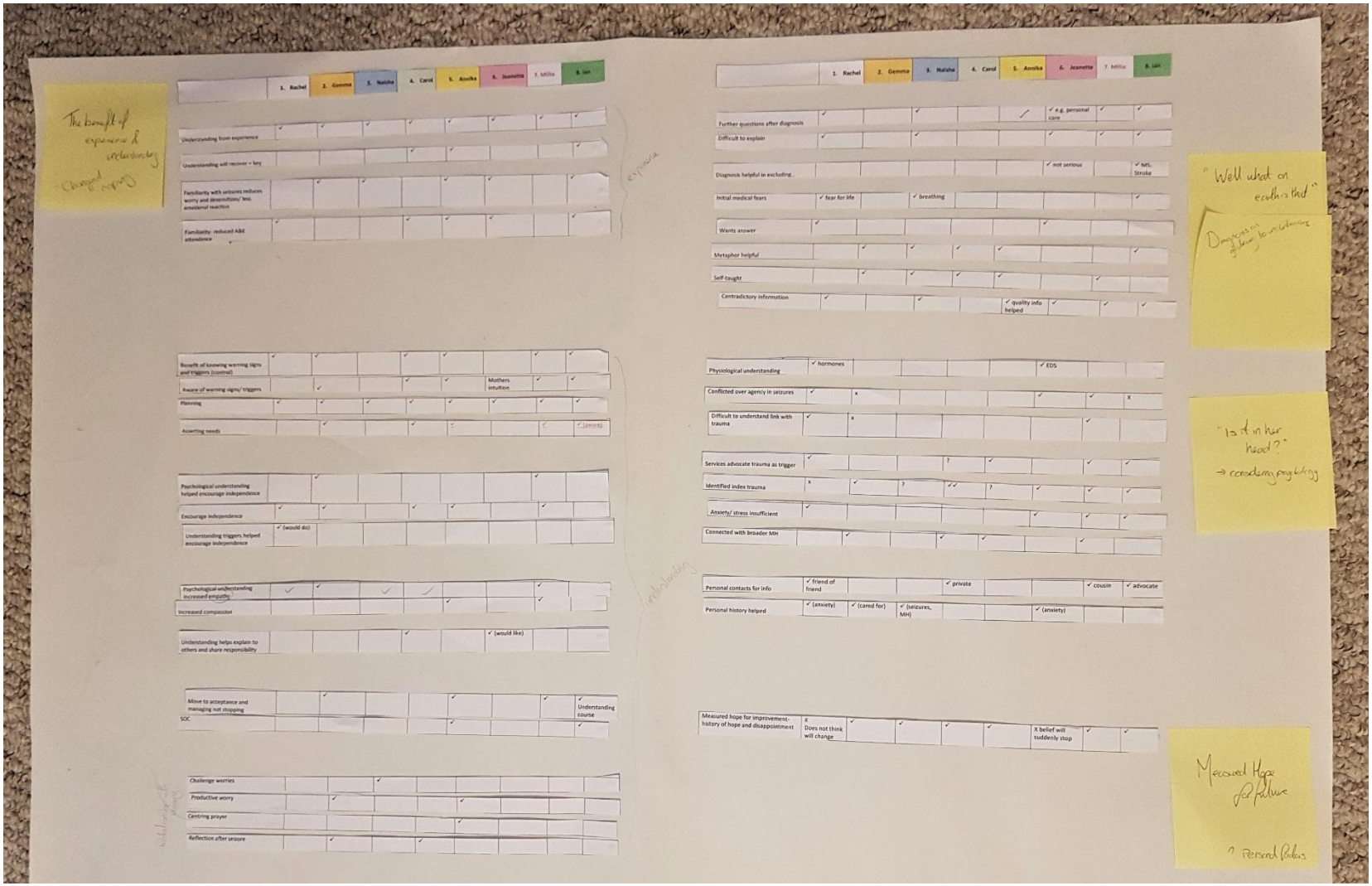
Appendix K: Example of emergent theme clustering for individual case



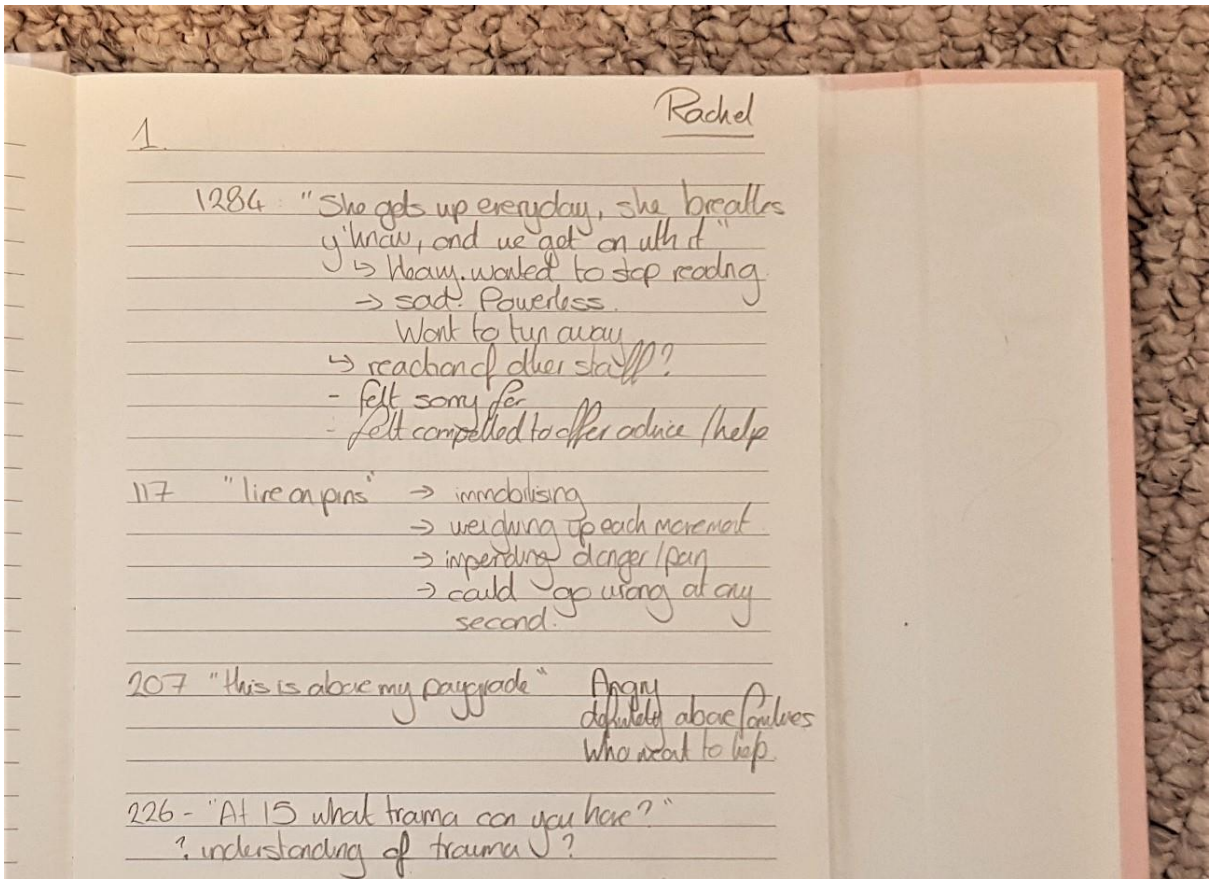
Appendix L: Example of visual theme clustering across cases (Theme 3)



Appendix M: Example of theme revision across cases (Theme 3)



Appendix N: Example extract from reflective journal



Appendix O: Supplementary illustrative quotes

Theme 1: The personal impact of caring		
Subtheme	**Participants contributing to subtheme**	**Example illustrative quotes**
1.1 'I thought I'd be living a different life.'	Rachel, Gemma, Carol, Annika, Jeanette, Millie, Ian	"It's not really what you signed up for" (Carol). "It's not how you thought your life was gonna be really but there you go, it's being a… we're a family and she's our daughter and we will look after her" (Jeanette). "I suppose I've always thought when I retire I would like to travel a bit more, my husband and I have got a few, various places we would love to visit but we haven't been able to do that and we keep saying: 'Well maybe next year', you know. It… we still want to but it's just… it's not possible at the moment" (Annika). "You just feel like everything is on hold really because we felt we couldn't go out and leave her at the beginning" (Carol). "There's definitely been a… been a grieving process almost… erm, on… on my side for… who Anne used to be… I think, who I used to be before I was a carer and also… for us as a couple, for how we used to be and how we are now" (Ian).
1.2 'I need to make sure you're safe'	Rachel, Gemma, Naisha, Annika, Millie, Ian	"Sometimes the dynamics were a bit different so sometimes it wasn't that equal role that you have in a relationship where you both take care of each other and look out for each other and… can be there for each other because, you know, when she was having a bad day with lots of seizures, she couldn't be there for me and there was just no alternative, there was just nothing that could have been done about that." (Naisha).

		"In a strange sort of way, it has sort of strengthened us and brought us together. More of the…and I…almost going back to the while we're fighting the PIP stuff, it's like, it is almost a bit of a: 'Well sod you, it's us two against the world.'" (Ian). "I won't even shout at her to tidy her bedroom because I'm scared that if I tell her off, I'll cause her to have another seizure." (Rachel). "We had to have all those horrible conversations quite early on it meant that we could be quite open with each other moving forwards. So now, I know… he has to talk to me about his mental health so that I can help him keep a lid on it and I guess that's helped me in opening up to him as well." (Millie). "I was looking after all the finances, erm, I was doing everything, absolutely everything- so he felt useless. He felt like he wasn't doing, and I didn't need him and that was so far from the truth." (Gemma). "When it first started, I really did smother, like completely smother her. Y'know we sort of like- if you could have bubble wrapped her and left her in her room not to move- then, then yea." (Rachel). "I'd say she probably resents me for not letting her do certain things… erm, y'know, like I wanna get the bus today, I wanna be normal and I'm like: 'Well, y'know, yesterday when you were stood at the bus stop you collapsed in a pile of mud right at the side of the road or you collapsed on the bus'- we've had that before- erm… 'so now I don't want you doing that.'" (Rachel).
1.3 'Head down, getting on and doing what needs to be done.'	Rachel, Gemma, Naisha, Carol, Jeanette, Ian.	"You just sort of, do you know what, it's probably, I'd say probably the best way to put it, I'd like to say we're paddling, but I think it's more like wading through mud is what we do on a day to day basis." (Rachel). "I don't know how to put it into words what it's like [seeing daughter in seizure] you just do it." (Carol). "I don't think you always realise how mentally it does affect you until you start thinking about how you deal with things." (Gemma). "I think I just go onto autopilot to be honest." (Gemma).

Theme 2: Navigating the reactions of others		
2.1. 'Getting pushed from pillar to post and back again.'	Rachel, Carol, Annika, Jeanette, Millie	"It was just pure fluke [getting to right specialist]." (Rachel). "I don't know who I go and speak to because the doctor just looks and me and says: 'Well there's nothing I can do, I'll just have to refer you back to X Neuro.'" (Rachel). "The mental health services were just sort of: 'well that's how it is, go away and get on with it.'" (Carol). "I have learnt you have to be prepared to be quite assertive and direct with people and ask to change practitioners if necessary and just keep pushing until you find somebody who you feel can work with the family member who is having the seizures." (Carol). "'We don't deal with these, this is a different problem and they should have told you that.'" (Annika). "I felt they were all…like she was being fobbed off by both sets of specialists and that the neurologist said: 'Well we're not interested, it's not epilepsy, that's what we deal with so you don't need us, you're not serious enough for us' you know: 'This is just, erm it's not very serious' basically and: 'Don't waste our time.'" (Annika). "It's frustrating, very frustrating because it's like a brick wall; you just smack your head against a brick wall each time being told: 'There is nothing,' 'There is nothing,' There's no magic wand,' 'There's no tablet' erm… 'There's no therapy as such.'" (Jeanette). "Apparently depending on what area you live in depends on what age you do CBT. So, we've had to wait until she was 18 and we're still not within the right area for her to be able to have it." (Rachel). "The exam board wouldn't allow her to sit it with a first aider and the college wouldn't allow her to go in without a first aider but they'd go and fight it if that's what we wanted to do." (Rachel).

		“About three years ago, erm… he was referred by the doctor to the epilepsy nurse but she was an epilepsy nurse and had, sort of, no- even though he doesn’t have epilepsy as well, it is just the non-epileptic seizures- erm, and she had no… she didn’t even know what it was, she didn’t even know it existed so there’s still a lot of erm… you know, grey- well, not even grey… black… lots of dead areas- you know, nobody knows anything about it! So, yea, it’s kind of, it’s difficult to know whether there are things there that we’ve missed or whether it’s just because there’s nothing there.” (Millie).
2.2. ‘Lived-in experience can be discounted’	Rachel, Gemma, Annika, Millie, Ian	“She’s not a baby anymore so I have lost control as to whether or not I am allowed, even allowed to go in, let alone speak to anybody.” (Rachel). “We live with it every day so we tend to know what they [people with NEAD] need. And we know as well if the seizure is worse or longer than normal.” (Gemma). “They don’t tend to listen, at all. And it’s like, they’ll ask how long a seizure’s gone on for and then be like: ‘Are you sure?’ And I’m like: ‘I’m absolutely positive.’ Y’know, I’ve not like made it longer or anything just for a laugh.” (Gemma). “I want to be talked to as an adult who has got understanding, you know, about how to help Joanne [daughter] manage and get through this and cope with it.” (Annika). “They’re [medical staff] not seeing her on a day-to-day basis, she’s never been ill enough that she’s been admitted to hospital for that sort of supervision. Therefore, the best people to… sort of, work these things out and know about it is going to be us, because we’re the ones living with it, isn’t it.” (Ian).
2.3 ‘People don’t know what it is’	Rachel, Ian, Gemma, Naisha, Carol, Annika, Jeanette, Millie.	“One of the other teaching assistants she’s like: ‘Well why? You shouldn’t be working!’ and he’s like: ‘Why shouldn’t I be working?’ and she’s like: ‘Well you have these do’s’, as she calls them. And he’s like: ‘I can’t help it, I don’t know when I’m going to have them’ and she’s like: ‘Well it’s dangerous’ and he’s like: ‘Only to me when or fall or whatever, It’s not dangerous to anyone else.’ (Gemma).

		“We’ve had it before where she’d collapsed at the side of the road and some woman had been screaming at her at the age of seventeen: ‘It’s disgusting that you’re drunk at 9 o’clock in the morning.’” (Rachel). “I think it’s harder when you’ve got people around you because you feel like you’re being judged for what decision you make and I think the hard thing is, what happens if I make the wrong decision?” (Rachel). “They [First Aiders] thought I think at the beginning that we didn’t really care because we… [her father] and I were just saying: ‘No she’s fine, just give her a blanket, if we could just wait here until it’s all finished.’ And they were wanting to call proper paramedics and things, we were like: ‘No it’s fine.’ (Carol). “When we… would be at home [when wife had a seizure], I would, you know, be able to talk to her without any interruption. I’d be able to, you know, play her the right music, it would feel…safe and warm. Whereas [in public] you know, people… some people would ask me if we wanted help, some people were just walking by and staring. It’s just…yea, it was just unpleasant, I guess and you’re always wondering about what other people are thinking even though it shouldn’t matter.” (Naisha). “I’m just wanting to sit with Joanne [daughter] and reassure her [following public seizure], keep calm and keep my voice calm but for others, when I’m talking to others my voice has to be different: ‘It’s okay, it’s alright, don’t call an ambulance’ you know, that kind of voice and: ‘It’s alright, it’s not risky and she’ll be alright in a few minutes’ and I’m going through all this and it’s a completely different tone of voice and then, you know, my attention is divided between them and Joanne and they’re saying: ‘Oh is there anything we can do?’ ‘No it’s fine, just…it’s okay, just keep calm, she’ll be alright… I’ll stay with her.’ So it’s like two conversations, trying to have two conversations at once.” (Annika). “Other people don’t know about this condition and then when they do know, it’s, kind of, they’re not quite convinced. I mean even other family member, particularly, you know, the next generation above us, both, both our mothers are a bit, kind of, sceptical about: ‘Oh you know, surely you can do something about that’ and: ‘Doesn’t she just need a firm hand’ and all that sort of thing so I think that is quite frustrating.” (Carol).

		"Joanne [daughter] had told me, that someone had said to her- I can't remember exactly what her words were but you know: 'Oh Joanne, just stop that, you're putting it on' and feeling quite, being a bit inpatient with her. I've had other people say to me: 'Is she just wanting attention is that what it is?' you know, and… I mean, always behind that is the assumption that she doesn't, you know, have to do this and she could stop this so I feel that part of my job is to try and educate people." (Annika). "A lot of doctors believe that this is a lot of old guff that somebody has made up. Y'know, they, y'know, we speak to the heart doctor and he says: 'It's not even a real thing and somebody's just made it up.' (Rachel). "I had to sort of pep talk and, sort of, remind her everyday: 'Well, you know, you loved your job'… it's like: 'Well you obviously aren't making it up, because if you were you'd stop now because you're not being able to do what you want to do.'" (Ian).
2.4 'Knowing I'm not the only person going through this, it helps.'	Gemma, Carol, Annika, Millie, Ian	"It's helpful to know that there's other people out there and I sometimes read posts on that facebook group and I think: 'Oh my goodness, how do they cope' erm, and, but erm… so that sort of solidarity is quite helpful, just to know you're not on your own. " (Annika). "It means I can then go back to him, either with having got it out my system and somebody's listened to me and agreed with me and that's fine so that we can move past it or I've ranted to somebody and they've said: 'Well, you know, if you think about it, X, Y, Z' and then I can go back and go: 'Right okay, I might have been a little bit hard or I might have been a little bit wrong to have thought of it like that so why don't we try it this way instead.'" (Millie). "Having somebody else who goes: 'Well actually yea I've had that' and you just know that you're not on your own." (Gemma). "I've come back [from meeting friends] feeling more positive, relaxed, quite a boost, it always, you know, gives me a boost and…erm, and that gives me, sort of re-news my energy I think in carrying on with the day, caring for Joanne if that's what's needed." (Annika).

Theme three: The importance of having an explanatory framework for seizures		
3.1 'There were no answers, no real answers'	Rachel, Naisha, Carol, Annika, Jeanette, Millie, Ian	"It wasn't until the EEG confirmed the diagnosis that I could really relax and think: 'Okay, well that's…it's okay, it's nothing physically wrong with her brain.'" (Annika). "Do you know what, if somebody comes back and tells me the answer is: 'This is it and there is nothing more we can do and now you're gonna live with it' I'd take that. I just… because then we'd know what we were dealing with, properly dealing with, y'know, and we wouldn't be like: 'Are we gonna be dealing with this for 6 months?', you wouldn't be in limbo." (Rachel). "We've kind of learnt about this largely from our own research." (Annika). "I don't think there's enough specific education for this type of disorder and it makes it hard because it is difficult emotionally, it's difficult to see… it's difficult practically, it's quite debilitating for a person and if you don't understand why… it's so much harder to support the person." (Naisha). "There's no answers, there's no answers. We just want to, want to know why, the big question: "Why?" which we don't know and where we go from here." (Jeanette). "We were looking for an answer- not that we've got an answer-answer- but when we were looking for somebody to tell us what it possibly was more so." (Rachel). "You don't find any answers, there was no answers, no real answers." (Jeanette).
3.2 'It's much easier to deal with if you have a story you can tell.'	Gemma, Carol, Annika, Jeanette, Millie, Ian.	"I don't think it's a very well-known condition, trying to explain to other people, what's happening is still quite tricky. Even medical professionals, some people haven't heard of it so you… you're constantly explaining but at least we can explain. Erm…before that, you're kind of like: "Well she's having these symptoms and we don't know why, and they don't know why." (Carol). "All anybody will say to me is that it was caused by a trauma but I'm like, at 15 what trauma could you have?" (Rachel).

		"In terms of noticing the triggers and the patterns and things like that, the looking at it from a mental health point of view, I feel made it easier for us to find the triggers. Because, you know, we've looked into when his mood changes and then that's coincided with an onset of seizures and things like that." (Millie). "It's better when we can put reasons to the seizures rather than like the other morning when he was in the bath, he went to stand up to get out the bath and had a seizure but we'd got no explanation for why he'd had a seizure. I don't know whether, y'know, he'd hurt himself and that… because pain can cause him to have a seizure. It wasn't particularly warm so he hadn't overheated. They're the ones that I find harder to make sense of and I know Colin finds harder to make sense of because there seems no reasoning for it and I think those ones frustrate him more because he can't say why it's happened." (Gemma). "I think a lot of it, for [my husband], is just…. just feeling pretty crap really that he's had another one, you know, and a lot of it is to do with his mindset I feel, afterwards, you know. So whilst it might not necessarily help the seizures, I think if I can help his mindset by getting him up and getting him out and getting him to do something rather than dwelling on it and feeling sorry for himself then in turn it's going to help his depression which will then help his seizures is, is sort of the way that I've come to look at it". (Millie).
3.3 'A whole different way of approaching the seizures'	Rachel, Gemma, Carol, Annika, Jeanette, Millie, Ian.	"I suppose understanding a lot more about stressors and triggers and how to manage them, they're not life threatening, erm… she will come through it. You know, all those sort of things together make up a… just a whole different way of approaching the seizures and so you become like, well , you know, people have all sorts of illnesses, physical as well as mental and that's how life is, you know, it's not… it doesn't need to define everything. It's what we live with but we can still live well with all of that." (Annika). "People are saying: 'Let me call an ambulance' [after public seizure] and I'm saying: 'No, It's fine.' Whereas when it first started I was forever calling an ambulance or taking her to the hospital." (Rachel). "We're getting better at being able to pinpoint when he might have one so I know when I can and can't leave him alone with the child." (Millie).

		"I have to make myself allow her to do that [go out independently] and encourage her to do that because she needs to." (Carol). "It's just treating it as any other disability. If it rears up, it rears up and we deal with it and if it doesn't, we just carry on as normal anyway." (Gemma). "I'm much more likely to sort of let it take its course. You know, I know that it'll pass." (Annika). "It's been gradual I suppose [change in caring style] and it's come though largely through understanding." (Annika). "Although we've known it's been coming [carer hospitalisation], we've waited instead of overthinking it again, we've waited to get the date so we know when it is and then we can start putting firm things in place." (Gemma). "I can get very wound up worrying about… even almost unconsc…subconsciously, you know, just automatically worrying: 'So, what's Joanne [daughter] doing now? Where is she? What's going on?' or, you know: 'How long will this last? Is she always going to be like this?,' all those sort of things and actually, what does that add to life?, you know. So these practices, these prayer based practices, help me to let go of that more easily, you know, I do that when I'm doing that practice every day but even during the day I'm able to notice when I'm starting to think like that and just start to let go, you know, because what's the point in dwelling and worrying on anxious thoughts?" (Annika). "I was much more, kind of, probably much more in-your-face with Joanne [daughter] which… probably talking more you know: 'Come on Joanne, it's alright, breathe, just breath' but probably… talking too much actually when I think about it. Erm… in the sense that it may not have been very calming for her, you know, she might have… because if she's trying to listen to me as well as have the seizure and gain control herself, it's quite a lot for a brain to deal with I think. So, erm… yea I think I talk less now." (Annika).

		“I didn’t have a lot of- well I didn’t have any understanding of it- when we first got together at all. So when he was spending, you know, days in bed following a seizure I was like: ‘I don’t understand this’ you know: ‘Just get up’ you know: ‘There’s people with epilepsy who can just get up and crack on afterwards, why can’t you?’ and I didn’t understand it.” (Millie). “I’m just a little bit more considerate now of the fact that it is an actual, you know, it’s not this made up thing in his head it’s actually something that’s happening to him so...yea, just, I’m just giving him a little bit more time and a little bit more consideration rather than just being like: ‘Ugh, get up’. (Millie). “What we’ve found out, especially over this past year, by not overthinking things and thinking: ‘What does he need?’ and: ‘What can I do to stop that?’ you can overthink it and go into overdrive. He doesn’t need wrapping in cotton wool, he’s big enough and daft enough to look after himself, it’s just when he’s having those seizures he wants a friendly, familiar face when he comes out of them and to know that he’s safe no matter where it’s happened.” (Gemma).

Paper Three

Executive Summary: The experiences of family carers supporting adults diagnosed with Non-Epileptic Attack Disorder (NEAD)

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Word Count: 1888

This report is a summary of a research study exploring the experiences of people caring for an adult family member diagnosed with Non-Epileptic Attack Disorder (NEAD). It was written to share the results of the study with those who took part in it. The reports talks about why the study was done, how it was done, what was found and what we would like to see happen next. A family carer for somebody with NEAD contributed to the development of this document through providing feedback on an initial draft.

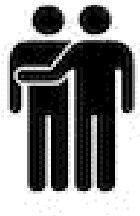
What do we already know?

NEAD:

- People diagnosed with Non-Epileptic Attack Disorder (NEAD) have seizures that outwardly look like epileptic seizures. Inside the brain, however, non-epileptic seizures are not accompanied by the same patterns of electrical activity.
- Getting diagnosed with NEAD can take a long time (Duncan et al., 2010) and there is not yet a standard treatment pathway (Gasparini et el., 2019).

Carers:

- Research with lots of different groups of carers has repeatedly found that caring responsibilities can negatively affect family carers' physical and mental health (Carers UK, 2019).
- Carers should be valued and treated as 'expert partners in care' (NICE, 2020)
- Research has found that people who care for a family member with NEAD have a low quality of life (Karakis et al., 2013) and are more likely to experience depression than those who care for a family member with epilepsy (Wardrope et al., 2019).
- A small amount of research has asked parents of children diagnosed with NEAD about their experiences. The research found parents felt upset, confused and afraid during their child's seizures. It also reported carers found the route to diagnosis and support difficult because of a perceived lack of awareness of NEAD amongst health care staff (e.g. McWilliams et al., 2016). We do not yet know if this is the same for people caring for adult family members with NEAD.



What we did

The study was advertised on Facebook support groups for people who care for a family member with NEAD, and also on Twitter. Seven women and one man were interviewed on Skype between October and December 2019. Four people were caring for a husband or wife and four were caring for their adult daughters.

Those who took part were aged between 28 and 62 years and had been caring for their family member for an average of four years.

Interviews were analysed using Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009). IPA is a research method which explores in detail how people make sense of a certain experience or event.

Why did we do it?

- The experiences of people caring for a family member with NEAD have not received much attention in previous research.
- It is important that both individuals with NEAD and their carers' support needs are included in any future treatment pathways for NEAD.
- Research with other groups of carers, such as those caring for someone with dementia, shows that improving carer quality of life leads to improvements in the person with dementia's quality of life also (Pinquart & Sorenson, 2006). The same might be true for people diagnosed with NEAD and their carers.
- We hoped hearing directly from carers, in their own words, would lead to improved understanding about the challenges of supporting somebody diagnosed with NEAD. We also hoped it would generate ideas for further research.

What we found

Three main themes captured carers' experiences:

1. The personal impact of caring,
2. Navigating the reactions of others and
3. The benefit of having a working understanding of seizures.

Theme 1: The personal impact of caring

Carers described how wide-ranging areas of their lives, including their identity, occupation, independence and relationships, had been impacted by their caring role. There was a clear prioritisation of the needs of the family member being cared for over the carers' own needs, especially during the early stages of caring. Mothers described how caring had interrupted the anticipated course of their lives. Many carers however, especially early in their caring role, did not think about the impact on their own lives:

> "There's no point letting it fester is there because you just have to think 'right this is how it is' and you find things to do and ways to cope and possibly make plans to try and improve the situation and you just…yea, you just have to keep going" (Carol)

Carers spoke about how hard it was to balance keeping their family member safe and encouraging them to be independent. Several carers did, however, describe how caring had increased the closeness of their relationship with the person they were caring for. Spouses often described how caring had strengthened their marriage in ways such as encouraging open communication, helping both partners feel comfortable asking for help and making them feel united against a common enemy:

> "We spent a lot of time together and… I think were quite open with each other quite early on, kind of because we had to be, which has worked really well for our relationship."
>
> (Naisha)

Theme 2: Navigating the reactions of others

All carers spoke of the significant challenges they faced in managing others' reactions to NEAD, whether the reactions of services, the general public or people in their personal lives.

Carers reported long waits to access services, often involving referral, discharge and re-referral to the same services. They were left with the impression that healthcare staff were not interested nor able to provide support and felt alone in supporting their family member:

> "Three years have been wasted, we feel, we feel like we've been floating around in Limbo Land for three years"
> (Jeanette)

Despite feeling responsible for managing their loved ones' seizures, most carers felt their experience and knowledge was not valued by services:

> "I just think that the lack of knowledge out there makes them think that families and the people who have the seizures can't understand it as well." (Gemma)

Carers described a widespread lack of awareness of NEAD both within and outside of medical settings. Managing public seizures was something often reported as being particularly challenging. In addition to fearing judgement at such times, carers also felt a need to educate people about NEAD and act as an advocate for their family member.

"People are looking at me as if to say 'are you nuts, because how can you leave your child like this?'"

(Rachel)

Carers valued being part of support groups. Membership of such groups was reported to provide validation of how difficult caring for somebody with NEAD can be. It was also reported to offer carers the opportunity for a more positive perspective of their own situation through comparison to that of others:

"There's people that aren't able to work, there's people that aren't able to leave the house because they're having multiple seizures a day so it [reading posts in support group] just sort of, kind of, keeps you grounded and makes you think 'actually, hang on a minute, we're doing alright here.'"

(Millie)

Theme 3: The benefit of having a working understanding of seizures

After diagnosis, carers sought information about the expected course of NEAD, how to handle seizures and how to identifying triggers and warning signs. For most, this information was not provided at the time of diagnosis and initially had to be obtained through personal research:

> "Put it into context: 'Okay they're not serious in the sense of being life threatening but they are real symptoms and you can do this and this to manage them' and, you know 'you can carry on with life in a normal way but become aware of the warning symptoms if you have them'. …that would have been a huge help at the time."
>
> (Annika)

All carers initially worried their family members' seizures had a medical cause. Over time, they described considering the role other factors, such as psychological factors, could be playing. Some carers linked seizures to a past trauma and found it helpful to understand why the seizures first started. Others were content with identifying triggers and warning signs:

> "So it's his brain's way of dealing with things that really, he doesn't want to face full-on and have to go through again so his brain just switches off in those occasions where there's been noises or around anniversaries [triggers]." (Gemma)

Two carers were still exploring possible medical causes for their family members' seizures and did not think that psychological factors were relevant:

> "They were on about: 'it's stress, it's stress, it's stress' and she was like 'but I'm not stressed!'"
>
> (Rachel)

Those who felt they had an understanding of their family members' seizures reported that this led to a change in how they cared for their family member. For example, carers described moving towards encouraging their family member to be more independent rather than trying to shelter them, and finding a way to incorporate seizures into life rather than trying to get rid of them. Greater understanding of seizures was also reported to help reduce worry for caregivers:

> "We laugh sometimes, we say, we tend to treat them like a petulant child at times or a toddler. You keep them fed, plenty of sleep, you know, water, not too hot, not too cold and they behave themselves better."
>
> (Ian)

Were there any problems with the research?

- Participants were all members of online support networks. The experiences of carers who are not part of an online support networks might be different.
- The research methodology used (IPA) aims to understand the experiences of the particular group of individuals interviewed. The results of this study are not necessarily applicable to everybody who cares for a family member diagnosed with NEAD.
- Only one person who took part was male and we therefore do not have much information about the experiences of male carers.

What does this mean?

- Carers described how having a framework to understand their family members' seizures changed the way they supported their family member, helped them feel more confident in their caring role and worry less.
- Quality information after diagnosis was reported to help carers understand their family members' seizures. It may be beneficial to include carers in interventions designed to help the person experiencing seizures understand their condition. This could have benefits for both carers and those they care for.
- Although carers reported that caring had resulted in significant changes to things such as their identity, freedom, relationships and ability to work, they prioritised their family members over themselves. In line with the Care Act (2014) the needs of carers should not be overlooked and they should be offered an assessment of their own needs.
- Based on the accounts of carers in the current study, helpful psychological support for carers may involve: assertiveness training to help manage the negative judgements of others, strategies to manage worry and strategies to increase self-care and continued engagement with personally meaningful activities. Need for psychological support should always be assessed on a case by case basis.

What next?

- Some of the problems carers reported facing were due to service issues. The development of a clear treatment pathway for those with NEAD, the inclusion of carers in appointments, increased awareness of NEAD and joint working between mental and physical health services would reduce some of the stresses carers faced.
- Research with larger numbers of participants could explore whether the results of this study can be generalised to other family carers of people with NEAD .
- Future research should measure the effects of psychological intervention for both the person with NEAD and their carer.

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